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AGENCY IN LEARNING AND E-LEARNING THROUGH THE LENS OF DISABILITY AND INCLUSIVITY

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ABSTRACT

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November 20, 2023

Through the analysis of ethnographic, qualitative data collected from students and their stakeholders at the University of Louisville, this thesis examines the experiences of students with disabilities in spaces of higher education, particularly virtual learning spaces. This research has illuminated systemic gaps in disability resources and accessibility within the landscape of higher education, restricting the agency of students with disabilities and their stakeholders.

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CHAPTER ONE: INTRODUCTION

Setting the Scene

The light of the computer screen buzzes electrically as I wait in the Microsoft Teams lobby for one of my participants to log into our meeting. The screen flicks in an instant to a middle-aged woman lying on her side in a hospital bed, her warm walnut skin aglow against the stark bleach-white sheets. Diane greets me warmly, apologizing for the setting in which she had to attend our meeting. I assure her that it is no worry and that I do not mind rescheduling our meeting for a more convenient time, though she replies that this was as convenient of a time as any because, due to her invisible disability stemming from a vital transplant, she routinely spends 24-72 hours in the hospital for care and treatment. Her experience is the most visually clear example of powering through the challenges of disability that I witnessed while collecting data for this project, and one of many lives I glimpsed to write about the experiences of students with disabilities at the University of Louisville.

This research began with the concept of investigating the role of e-learning and distance education, with a particular focus on how these forms of learning can be utilized to expand access to higher education for disabled students. Interview questions throughout the data collection process focused largely on e-learning, but the conversations often shifted to the wellbeing of disabled students altogether. It seemed like there was so much more to be said about the experiences of disabled students and their key stakeholders at the University of Louisville (UofL) – so much that this collection of experiences has guided the expansion of my thesis topic since participants began to respond to my recruitment materials in late spring of 2023. In this thesis I respond to my interviewees' narratives by situating discussions of e-learning in the context of their wider teaching and learning experiences at UofL.

While I did not initially seek to evaluate the quality of support for disabled students at UofL, perhaps the data I have collected here can help if such an evaluation was ever conducted. As a disabled student and researcher myself, I have ethnographically examined the experiences of students with disabilities and their stakeholders at the University of Louisville, intending to understand the array of experiences within the institution. I initially sought to demonstrate the potential of e-learning as a tool for maximizing agency and accessibility in higher education, though this research has grown to cover many more questions of access within institutions of higher learning. This project may help to inform a set of key findings and suggestions for the University of Louisville regarding disability policy and accessibility.

The totality of the data I have collected and analyzed suggests that there is a collective feeling that, with the support of university faculty and staff, disabled students *should* feel supported. Why, then, was it not the case that all of my participants felt fully supported? Through my research, I have found both commonalities and discrepancies in experience that suggest that institutional limitations and a larger social predisposition toward inaccessibility are responsible for the lack of complete support for disabled students at UofL. This thesis argues that institutional barriers limit the agency of students with disabilities and their institutional stakeholders, supporting this point through the analysis of ethnographic data collected through a series of interviews with staff, faculty, and students with disabilities at the University of Louisville.

Significance and Relevant Perspectives in Research

This research was and continues to be necessary because the perspective of disabled individuals, women in particular, are largely absent from scholarship on higher education (Battles 2011; Dunn and Burcaw 2013). My perspective as a disabled, female student has provided me a unique and important vantage point throughout this research process, both to gain access to peers with disabilities and to process the data I have collected from a disabled point-of-view. My disabilities include fibromyalgia, chronic fatigue syndrome (CFS), major depressive disorder (MDD), and autoimmune deficiencies, all of which impact my learning in a variety of ways. Though these illnesses present a difficult set of obstacles in the process of my own learning, this identity equips me with the empathy, understanding, and situated experiences to comprehend and represent the experiences of similarly disabled individuals (Ginsburg and Rapp 2020). Further, my experience in coping with chronic illness through the process of being both an undergraduate and a graduate student at the University of Louisville assists in relating to other disabled students with similar experiences (Hartblay 2020). My experience as a disabled woman in higher education is a vital piece of this puzzle and inseparable from my motivations to complete this research (Battles 2011; Durban 2021; Hartblay 2020).

The narratives of my interviewees are also valuable to the scholarship on disability and, in particular, the wellbeing of students with disabilities in spaces of higher education. Their perspectives are systemically missing from main bodies of scholarship for reasons directly related to their social identities of being disabled, and some participants share identities that are further marginalized by society such as trans, femme, or Black. I further explore these intersectional identities from the perspective of participant narratives in Chapter Four.

Because my disabled experience is the only perspective I have, it is hard for me to fully quantify what it means to be disabled in these pages; I do not have another perspective to compare it with, and I can only imagine what it would be like to be able-bodied because I have never had that experience (Dunn and Burcaw 2013). In this way, it is hard, or even impossible, to separate my "disabled" experiences from "other" experiences. This is an experience that student interviewees spoke to as well, so I further explore these narratives and the concept of disabled identity in Chapters Three and Four.

Being a disabled student, it is easy to feel like I fall short in comparison to my peers. Many days – sometimes more than half of my days each week – are spent in my bed. However, I am not always lying down; in fact, for the majority of the time I spend in my bed, I am attempting to be productive. Much of this thesis has been written as I sit cross-legged in bed, trying to experience as little discomfort as possible at any given time. This is how I did much of my college coursework for the last six years, propped up by pillows with my laptop on a makeshift desk in front of me and surrounded by things that I may need: more pillows, various drinks, blankets, snacks, medicines, my coziest sweater, and other odds and ends that I have found helpful to have near. Prioritizing being in a comfortable, familiar space most of the time where such items are readily accessible is one of many ways I cope with chronic pain and disability. Something as simple as choosing the wrong clothes to wear – a too-itchy t-shirt or jeans that pinch the skin on my legs in a certain way – can trigger deep and intense pain. On days when my body is feeling particularly fragile, each move of a muscle risks pain or injury. Prioritizing comfort and security becomes a survival tactic when you are avoiding exacerbating chronic pain. You are never not hurting with chronic pain, that is what makes the pain "chronic".

These experiences made going to in-person classes difficult for me as a college student, and therefore not fully accessible. I have to be constantly aware of my surroundings and appraising my physical state to keep myself safe and functioning, which can be both exhausting and distracting. This is an experience that some student participants also spoke to, which I will elaborate on in its own section. Though I have been experiencing some of my disabling conditions for my entire life, I was not diagnosed until I was 20 due to a lack of quality healthcare. The symptoms that I experienced that were indicative of fibromyalgia such as chronic pain, fatigue, gastrointestinal illness, and migraines were blamed on things like hormones, stress, and diet. It took years of pursuing appointments with specialists, bouncing from one to the next, to get some answers, though those answers are still incomplete today.

My experiences as a disabled student sparked the desire to do research on the topics of disability and education, particularly virtual education, but I did not expect the level of need I was met with when I began recruitment. More than one student reached out to me with a lengthy email detailing their frustrations with their disability and the

University's access to resources and support for disabled students, indicating to me that they had long desired someone to talk to about their experiences, but were unsure who to turn to. In the following sections, I discuss the institutional context of my research and the methodological and theoretical frameworks in which I conducted it, including key references and academic foundations.

Site Background: Introduction to UofL and Disability Resources

The University of Louisville sits in the heart of the city of Louisville, Kentucky with over 20,000 students enrolled during the academic year. Many of the functions of the surrounding community, including the social and physical landscape, are rooted in collaboration with UofL, and vice versa. This symbiotic partnership between the city and the university drives innovation, creativity, and progress in the community.

The University of Louisville's primary resource for students with disabilities is the Disability Resource Center (DRC) which can assist disabled students in a variety of ways. The main resource that they offer are course accommodations which, for qualifying students, can include extra time on exams and a regulated test-taking space, flexibility with course deadlines and attendance, providing closed captioning on all video content and other accessible digital content, supplying aid devices such as screen readers and interpreters, and so on. DRC accommodations have been listed in order of frequency of use according to stakeholder data collected through this research, as the most common accommodations are exam- and assignment-related.

The University of Louisville is also home to the Kentucky Autism Training Center (KATC), which assists autistic UofL students through college, supplies resources to autistic individuals and their caretakers, and trains K-12 teachers and first responders in evidence-based practices for providing services to autistic individuals. I will elaborate further on both the DRC and KATC in sections of their own within Chapter Two.

Conceptual Framework: Anthropology and Agency

Though I did not start my undergraduate college journey at UofL, I did complete it here, and immediately leapt into a graduate track in my field of study, Cultural Anthropology. I have been enrolled at the University of Louisville for six years now, and I have been in love with the study of anthropology for just a little bit longer. UofL and our Anthropology department did more than their fair share in convincing me that I had made the right decision to pursue this field by providing personal support and a well-rounded curriculum rooted in values that are important to me. I have learned too many things to list here, but, most importantly, they have taught me the importance of grounding scholarship and academic practices in the community around us.

If anthropology is the study of humans and all things human, and cultural anthropology focuses on the social aspect of human experience, then what is the function of the field of study? In part, cultural anthropologists develop a narrative of human histories, behaviors, and experiences. Historically, this has looked similar to sociology and history, even encouraging collaboration and amalgamation between the studies. What makes the present age of cultural anthropology distinct from these fields is its vantage point from within humanity, as opposed to outside of it. Anthropology, particularly cultural anthropology, is deeply experiential in that all things social and relational are inseparable from individual experiences.

Thus, today I see there being two main purposes for the field of cultural anthropology: 1) to identify and understand the cultural landscape of the world around us, and 2) to utilize these studies to advocate for those communities and individuals who have been identified as more vulnerable than others. Anthropology is in a unique position to do so from the aforementioned perspective of being set within the human experience and working from the understanding that all human experiences are social and interactive.

Since I am doing this research through the lens of cultural anthropology, I am looking at disability through a cultural lens and through the concept of agency. This is part of the reason that I have included in study interviews students who self-identify as disabled, without necessarily having a formal diagnosis. Including these individuals in my sample group demonstrates the respect for an individuals' own experiences and agency to inform their sense of self - a representation of their identity more intimate than a doctor can ascribe them. This is not to disregard the importance of medical diagnoses and appropriate treatment, but to acknowledge that not all individuals with disabilities have access to medical diagnoses and treatment, and that an absence of access does not make them any less disabled than someone with a formal diagnosis.

As Ahearn defines it, agency is "the socioculturally mediated capacity to act" (2001: 112). This definition acknowledges that the ability to *act* can be hindered by social constructs and interactions, rooted in the power dynamics of a particular social context.

Agency is vital to the discussion around disabled experiences because the voices of disabled individuals have been systemically silenced throughout history by means of censure, erasure, and sometimes even genocide. Thus, the agency of disabled individuals should be centered and advocated for in research on disability and related experience (Hartblay 2020). The conceptual context of agency is vital to my research, a thread woven deeply through the experiences of the participants in this research, both student and stakeholder.

In this thesis, I have attempted to use primarily person-first language as opposed to identity-first language, which is a particularly contentious topic in the disability community and advocacy spaces. This is meant to prioritize the person over their disability, highlighting the individual over their perceived identity, in an effort to be more inclusive (Flink 2021). Some people with disabilities prefer identity-first language, but the vast majority of scholarship suggests that we center the person over the disability unless asked specifically to do otherwise (Dunn and Burcaw 2013; Flink 2021; Ginsburg and Rapp 2020).

Literature on the subject of learning pedagogies and methodologies has helped me to frame the paradigm in which I collected data and subsequently analyzed it. These sources helped to shape my perspective within the bigger picture regarding the efficacy of e-learning as it relates to other styles of learning. The pedagogical texts in this field that were most informative and useful during preliminary literature research are rooted to some extent in active learning, inclusive teaching, online education, or some combination of these topics (Eyler 2018; Weimer 2013). The role of the disabled learner has always been at the center of my research and is important to frame this role through texts about educational and learning practices, particularly more recent and inclusive efforts in engaged or "active" learning and an understanding of the biological and emotional processes involved in the process of learning. The engagement of both students and faculty in learning practices are exercises in agency, which can be limited either structurally or by individuals higher than them within the institutional power structure.

This research into the experiences of UofL student with disabilities and their institutional stakeholders and allies is set within the paradigm of research into inclusive education. For context, my understanding of inclusive teaching methods is heavily rooted in Maryellen Weimer's text *Learner-Centered Teaching* (2013), which demonstrates the necessity of decolonizing the classroom by recentering the power dynamics such that students regain a great deal of agency in the process of their own learning (see also Eyler 2018). This process of power-shifting is relevant to the study of disability in learning spaces due to the excessively skewed power dynamics that disabled students can experience in the classroom (Titchkosky 2011). Understanding the setting(s) in which disabled students are attempting to navigate whilst enrolled in higher education has proved important in situating the data collected through this project, which relies heavily on student testimony regarding learning and VLEs, or *virtual learning environments*, (McAvinia 2016).

Lastly in this section, it is important to acknowledge that this research in both theory and practice is an exercise in institutional ethnography, a form of qualitative data that assists in the analysis of large social constructs from many potential vantage points, both internal and external. Institutional ethnography in this research takes the form of considering data collected from institutional agents of the University of Louisville through the lens of accessibility and inclusivity, particularly as it relates to students with disabilities, to draw conclusions about the physical and cultural institutional space (Devault 2006; Sutton 2021).

Conceptual Framework: Learning Methods and Anthropology of Disability

The framework of scholarly literature from which this project was built fit into two main categories: evaluating E-Learning environments and the Anthropology of Disability. Below each subheading in the following paragraphs, I explain the relevance of each category of literature to my research and what collective, overarching themes are represented by each field of literature.

Evaluating E-Learning Environments

This is the realm of literature that has informed my understanding of the practice of using e-learning spaces and their differences from traditional classrooms from the perspective of both the learner and the instructor (McAvinia 2016; Phipps and Merisotis 1999; Moreira 2016). Many texts which provide the basis for evaluating the effectiveness of e-learning spaces are most relevant if they come from recent research, giving the intensely dynamic nature of technology in the current era. Scholarship in this field seeks to equally explore the limitations of technology as a means of learning and its potential benefits as an educational tool.

Questions of accessibility have always been relevant to the conversation around the integration of technology into education (Phipps and Merisotis 1999), however there is potential for VLEs to expand access as well (McAvinia 2016). It is necessary to address the limitations of technology-based learning in such research in order to properly contextualize the data collected. Students may face a variety of challenges with technology – with or without the added potential challenges of disability – all of which must be addressed to alleviate these difficulties and prioritize accessibility (McAvinia 2016). Much of this scholarship is written from the viewpoint of educators, which means that the inclusion of student perspective is a necessary effort in this literary field. These texts, among others (cf. Jensen et al. 2020; Moreira 2016), situate the themes of identity and agency through the coordinated lenses of education and technology. The collective literature around learning, particularly in VLEs, engages the theme of agency through the nature of self-regulated learning in engaging the individual learner's agency, or capacity to act (Ahearn 2001), in a larger capacity as a means of their own learning.

Though my research has been situated at the University of Louisville in Kentucky, U.S., the literature on educational praxis and pedagogies are not limited by national borders. A great deal of scholarship has emerged around the world which is relevant this research by common subjects of accessibility, efficacy, and inclusivity (Keengwe and Kungu 2019; McAvinia 2016; Phipps and Merisotis 1999). Such publications help to contextualize my research within the international community and broader applications to online learning in higher education around the world (Keengwe and Kungu 2019). The representation of a diverse set of literature functions to create a well-rounded conceptual framework, helping to better inform my own research and subsequent research while affirming that methods utilized in similar scholarship are held to appropriate standards.

Pedagogical debates around e-learning and distanced education have been taking place since the 1990s (Phipps and Merisotis 1999), but the jury is still out when it comes to a consensus on the best applications of e-learning (Keengwe and Kungu 2019). The coronavirus pandemic (Kyei-Blankson et al. 2021) exacerbated the immediate need to expand VLEs for an indefinite period of time. It is also helpful to understand the criticisms of framing e-learning as a boon of accessibility, through the lens of *authentic accessibility* (Lee 2017). It is easy to overlook the ways that VLEs can restrict accessibility while espousing the beneficial aspects of virtual learning, though it is important to consider the question of access from all available perspectives.

Anthropology of Disability

The body of literature regarding disability in anthropology is vast and is largely rooted in exploring the institutional and historical parameters of disability as both a condition and an identity (Crow 2014; Ginsburg and Rapp 2020). As in most anthropological research, there is an increased focus on personhood and the utilization of disability as a lens through which to consider relationships with oneself and their environment (Battles 2011). In my research, this anthropological focus is represented through the lens of agency. Many texts on the anthropology of disability seek to explore the experiences of people with disabilities and their role in the literature around disability. Further, they ask: what does it mean to be disabled? Most relevant literature agrees that this experience varies both by individual and by social context (Crow 2014; Ginsburg and Rapp 2020). The agency of the disabled individual is becoming more central to studies of disability as a way to produce more accurate representation and inclusiveness in both scholarship and practice (Battles 2011; Durban 2021; Erickson 1982; Ginsburg and Rapp 2020; Hartblay 2020). My thesis seeks to contribute to this literature by focusing on the agency of students with disabilities and their key stakeholders, as well as centering my experiences as both a student and a researcher with disabilities.

In emerging literature from the perspective of the person with disabilities, authors discuss candidly the experience of being disabled through the lens of their ethnographic research topic and, conversely, the importance of ethnographic research through the lens of disabled identity (Dunn and Burcaw 2013; Ginsburg and Rapp 2020; Hartblay 2020). Though the experiences of individuals with disabilities can vary by person and environment, our collective experiences inform our concept of self and identity, which can be heavily impacted by the limited agency that we experience in some public settings (Ahearn 2001; Crow 2014). Useful texts in this field encourage prospective disabled researchers to participate in scholarship regarding disability in order to recenter the agency of disabled people and the larger community (Durban 2021; Ginsburg and Rapp 2020; Hartblay 2020). By recentering the voices of disabled individuals in their own narratives, perhaps a clearer and more accurate picture of the lived experiences of disabled people can be formed, resulting in better representation and more effective cross-community interaction (Battles 2011). Though anthropology has seen a historical lack of disabled and otherwise marginalized researchers, there is a concerted effort to draw a more diverse group of scholars into the field as researchers today (Durban 2021; Ginsburg and Rapp 2020; Hartblay 2020).

The impactful and concise article “Lying-Down Anyhow: An Autoethnography” (Crow 2014) follows the firsthand experience of a disabled woman, author Liz Crow, who feels immense physical, mental, and emotional relief through the act of lying down. Without needing to state what her physical disability is, Crow effectively communicates to her audience the release and relief she feels in lying down. She describes this act as being interpreted as social, political, and even offensive in varying forms of public space; it is an act that shifts how others interpret her presence and identity. These experiences in public spaces can range from complete invisibility to beratement and abuse, and anything in between, which impacts her own view of herself over a period of time. Like other key anthropological texts regarding the subject of disability, this text engages directly with the theme of identity by articulating key experiences through narrative and reflection. Agency is represented in her choice either to lie down and give into the physical need for relief, deciding against the social expectation to not lie down in public. This action employs Crow’s agency when she refuses to sacrifice her own comfort for the sake of social acceptance and palatable visibility.

I relate intimately to Crow’s conundrum and find myself weighing these options almost constantly when in public spaces. Do I rest in public spaces and face the eyes of viewers around me? This option comes with confusion on the faces of people my own age wondering if I’m waiting for someone and the mutters-under-breaths of persons older than me who think it silly or soft of me to need a break. The medium of autoethnography allows room for Crow’s creative style of writing and is an effective means of direct communication with her audience. The accessibility of the narrative of Crow's experience through autoethnography allows the audience to get a glimpse of her perspective as a disabled woman in public, communicating a deeper understanding even for a reader who does not personally have a disabled point-of-view (Crow 2014).

Another popular autoethnography-like framework that is relatable to me and other people with disabilities is referred to as Spoon Theory and comes from the story of how the author, Christine Miserandino (2003), explained to her friend what it is like to have lupus. Miserandino begins by handing her friend 12 spoons, which she explains represent the limited amount of energy that she has to spend for the day. Every task – and every critical segment of every task – costs a spoon, or a portion of the finite energy a chronically ill person has for one day. The actions of getting out of bed, showering, putting on clothes, making food, eating, and sometimes even making decisions each take a spoon. Some intense tasks take more than one spoon. Sometimes you overdo it, and overspend your spoons for one day, and then have to begin with significantly less spoons the next day.

Though I did not find academic scholarship on the topic of Spoon Theory, there are many casual discussions of it and its relevance to the experiences of people with disabilities such as chronic fatigue on the Internet. One student participant in my own research, August, mentioned it passively a couple of times, with the assumption that I would know what it meant, and I did. My mother, who is also chronically ill, introduced me to Spoon Theory when I was younger to explain how she was feeling, and I have found it useful in framing my own experiences, too. Such experiential overlap is a powerful testament to the usefulness of metaphors like Spoon Theory in communicating the experience of chronic disability and thus is a standard reference for many people with chronic illness(es). Regarding Spoon Theory, August said, “I try to be really aware of my mental state every single day, every single moment. And if I feel like I'm gonna have a little spoons day, like in the next day or two, I'll just preemptively do it when a lecture day, that way I've got more spoons on a [practical learning] day.”

Research Design and Methodologies

In this thesis research, I have utilized two methods of qualitative data collection conducted under the approval of the UofL Human Subjects Office (IRB#23.0146): interviews and autoethnography. All data from my interviews with student participants was documented through transcripts, extensive fieldnotes, and data tables.

Two sets of recorded interviews were conducted with a total of 15 participants, all of which have been given pseudonyms. One set of interviews was conducted with seven students at the University of Louisville, including both graduate and undergraduate students, all of whom self-identify as disabled and have taken at least one virtual learning course. Student participants were either currently enrolled in courses or had just finished their last classes needed to graduate within a week of the interview being conducted. The students’ self-identified disabilities include ADHD, anxiety, autism, depression, diabetes, dysautonomia, fibromyalgia, and Hashimoto’s disease, among other unidentified and undisclosed chronic ailments.

My decision to include student participants who self-identify as disabled is an effort to be inclusive of individuals who experience disability without a formal diagnosis, and thus do not have access to accommodations through the University’s Disability Resource Center (DRC). I recruited student participants through a digital flyer sent via email initially from either myself or my advisor, Dr. Angela Storey, a recruitment tactic which intentionally cascaded into snowball sampling from there. This form of recruiting helped to broaden my sample set of participants (Schensul and LeCompte 2013), preventing the sample from being skewed towards individuals that only I knew due to specific social circumstances, but still fit my designated sample frame: students currently enrolled at UofL, identify as disabled, and having attended at least one online class. Some other faculty and students also helped to spread my recruitment email to student participants, as did the DRC. It is important to note that the DRC assisted me in recruiting students because it may have influenced the sample of research participants to more likely include students who utilize the DRC. However, not all of my student participants did utilize the DRC: of the student participants, five utilized accommodations through the DRC and two did not.

The other set of interviews were conducted with eight institutional stakeholders: three staff, four faculty, and one person who is both faculty and an administrator. These stakeholders were individuals who engage with or support students in instruction, including representatives of institutional efforts to further include and accommodate students with disabilities, such as a representative of the Disability Resource Center at the University of Louisville, a representative of the Kentucky Autism Training Center which is hosted by the University, and a representative of the Delphi Center for Teaching and Learning, as well as faculty who teach online courses. I identified these individuals by their institutional roles, so recruitment was done through a combination of targeted and snowball sampling (Schensul and LeCompte 2013).

Autoethnography in this project includes my perspective as a disabled woman in the role of student and researcher at a large university. I have taken online and traditional face-to-face classes with the University of Louisville and can speak to the positive impact that having the option of online classes had on my ability to learn, especially as an undergraduate student. Individuals with disabilities have for too long been excluded from the scholarship around their own conditions (Ginsburg and Rapp 2020), and thus it is important to empower people with disabilities to participate in research rooted in their own experience. Autoethnography can be a powerful tool to reclaim both identity and agency (Crow 2014). As such, my point-of-view on this topic is valuable and has contributed positively both to my own research and the larger literary framework around disability. Autoethnographic data is present throughout this research in the form of reflexive fieldnotes and reflective narrative.

The following chapters will explore these concepts through the experiences of research participants and my analysis of collected qualitative data. In Chapter One, I have laid out the conceptual framework of my research along with the functions of my research such as methodologies, background, and the reclamation of identity and agency. In Chapter Two: Institutional Stakeholder Perspectives, I will describe the data collected from interviews with individuals who participate in or assist in facilitating the learning processes of students with disabilities at the University of Louisville. In Chapter Three: Personal Experiences of Students with Disabilities, you will read the firsthand narratives of UofL students with disabilities who have experience with online learning. Chapter

Four: Analysis and Intersections, will serve to evaluate the data from Chapters Two and Three, situating it in relation to relevant scholarship and appropriate cultural context. Chapter Five: Conclusion and Recommendations, will summarize the information gathered from this research and utilize the analysis to identify systemic gaps in accessibility and agency.

CHAPTER TWO: INSTITUTIONAL STAKEHOLDER PERSPECTIVES

In this section, I will discuss the data I collected from institutional stakeholders. I situate them within the context of the University of Louisville, which I discuss as a microcosm of larger social patterns. After introducing these perspectives, I will tie the concepts that they introduce back into my literary and conceptual frameworks in Chapter 4. The institutional stakeholders in this research include one representative each of the Disability Resource Center, Kentucky Autism Training Center, and Delphi Center, four current faculty members at UofL, and one current administrator who is also a faculty member. This chapter will utilize data from all of these participants in the order that follows: Dylan from the Disability Resource Center, Frank from the Kentucky Autism Training Center, Rowan from the Delphi Center, and then I will cover data from all of the instructors together beginning with the "Instructors" section and on through the rest of the chapter.

Disability Resource Center

The Disability Resource Center, or DRC, is the main resource available to University of Louisville students with disabilities. The DRC connects students with disabilities to resources that can help students with proper documentation of their disabilities to succeed on an even playing field with their peers, to help mitigate the negative impacts of disability upon a student's learning experience. Relevant resources the DRC can provide include course accommodations, a resource coordinator, electronic aids, and accessible textbooks (audio, Braille, e-books, etc.). The DRC is located within Stevenson Hall, a central spot in the heart of UofL's Belknap Campus, and is staffed by six coordinators and assistants at this site. There is only one additional person who coordinates DRC functions for the Health Sciences campus, which is located about 3 miles north of the Belknap campus' center (Disability Resource Center 2023).

I spoke with an individual who works with the UofL DRC on the Belknap campus; they will be referred to as Dylan throughout my writings. Some of their responsibilities include processing applications for disability resources; conducting meetings with qualifying students; discussing, crafting, and assigning accommodations for qualifying students; outreach both on campus and off; and conducting and attending trainings for students and colleagues. Dylan answered questions thoughtfully, eyes sparkling with kindliness when engaging their knowledge on a topic so dear to them. Dylan stated that a large component to the work that they do requires keeping an open mind and remaining receptive to new experiences and information. They suggested that just because one student experiences a disability one way does not mean that the next student will have that same experience or need the same assistance, thus it important in their position to not generalize, assume, or insert bias, to the best of their ability.

My understanding of Dylan's role in more general terms is that they are meant to either be a support system or to help establish one when necessary for students with disabilities at UofL. From Dylan's interview answers, it seems that they are willing to be that support system if no one else is. Dylan seems to truly love the work they do, spending a lot of time thinking about advocacy and, though they rarely have to, they are willing to defend their students when necessary. Dylan’s approach to the position with the DRC has been informed in part by former work as a special needs teacher and previous work with the Arc, a nation-wide community-based organization that advocates for the human rights of people with disabilities, informed by the lived experiences of those people (The Arc 2023).

Dylan thoughtfully remarked that the University, and society as a whole, could benefit from universal accessible design and wishes that it was more of a priority. Both students and stakeholders that I interviewed afterward went on to speak on the same topic: that buildings and learning spaces do not adequately reflect the inclusion we claim to foster as an educational institution. Dylan advocates for universal design and general accessibility, saying that it only helps people to act inclusively and is not harmful or exclusionary to anyone.

Dylan spoke to the experience of COVID limiting routine functions and forcing an abrupt transition to virtual classes. This put stress on everyone, though they suggest that this began a process that has ultimately expanded accessibility in learning in the long run. Due to the impact of COVID upon learning spaces, more students were confronted with the option of virtual learning, an option that they may not have otherwise experienced. Dylan considered that perhaps the shared traumatic experience of COVID also opened up the conversation around mental health and lessened the stigma around discussing it and seeking help, increasing overall understanding of a particular kind of disability.

From their experiences working with the DRC, Dylan suggested that faculty should have more of an awareness of disabilities and the variety of disabled experiences and needs. Dylan stated that there have been previous efforts to include and unite students with disabilities that were sidelined due to COVID, such as the peer coaching program, and hopes that someone will breathe life back into these student-driven initiatives. Regarding the efficacy of VLEs, Dylan noted that when meeting with students virtually, it is harder to communicate as effectively because they cannot see the students body language and social cues in the same way, an experience that instructors mentioned in their interviews as well.

Kentucky Autism Training Center

The Kentucky Autism Training Center seeks to connect the local Louisville community and larger state of Kentucky as a whole with resources for autistic individuals and their caretakers. Their advisory board is community-based and comprised of an equal number of both guardians of children with autism spectrum disorder (ASD) and field professionals (Kentucky Autism Training Center 2023).

I spoke with a representative of KATC who chatted enthusiastically about the work that they do with students with autism. They described that they work directly with a group of students with autism at the University, all of which have vastly diverse needs ranging from high levels of need requiring frequent hands-on assistance throughout the day to help them function, to lower levels of need including things like weekly check-ins, goals, and activities. This program within the Kentucky Autism Training Center assists students with the transition to college and the journey throughout. It is supposed to be limited to accept only eight students, though they routinely accept more than that. The representative I interviewed, I will call them Fran, spoke highly of the students under their advisement, speaking with great pride in their success. My conversation with Fran was filled with heartwarming anecdotes and student success stories, each memory a treasured piece of their heart.

Another large part of the work that the Kentucky Autism Training Center does is establish training sites in approved schools across the state that prepare teachers to better instruct and interact with autistic students. They attempt to serve as many people as possible through the training site and distribute resources evenly throughout the state, which makes the selection process for a new annual training site a tricky one. The last of KATC’s major duties is to train first responders to safely assess and respond to a crisis in which an autistic individual is involved.

They have helped to establish the “Yellow Dot Program” which aims to educate autistic individuals, their caretakers, and first-responders to utilize or recognize a sticker with a yellow dot on their vehicle to signal that there is an individual with specific medical needs in the car and to respond appropriately, utilizing intervention or emergency information from trainings also hosted by KATC. The sticker alerts first-responding personnel that there is a folder within the vehicle, also marked by a yellow dot sticker, containing vital medical information about the individual(s) that might need medical assistance and what kind of assistance they may need such as significant diagnoses, allergies, and important medicines (Kentucky Autism Training Center 2023).

Another perspective on KATC is represented by a student participant who I will refer to as August and whose experiences I will discuss further in Chapter Three. August, who is autistic themselves, criticized KATC for their interpretation that the center utilized an approach based in Applied Behavior Analysis (ABA), saying, “That autism center practices and advocates for applied behavioral analysis, which fundamentally, they're just trying to change who autistic people are. They're just trying to get us to behave in neurotypical ways.” I could not find information regarding ABA on KATC’s website, which lists many informative resources on the subject of autism. I do not know if this means that ABA is no longer a framework utilized by KATC or that I just missed the information (Kentucky Autism Training Center 2023). Since I did not interview any students who utilized services through KATC, my research cannot speak to that perspective or definitively state whether or not ABA is a utilized framework. This limits my ability to fully assess differences in approach to support for autistic students.

A cursory look through KATC’s webpage shows me that they have an immense collection of information on a variety of subtopics under the general topic of autism. Though the site holds bountiful resources, it did not feel easy to navigate to me and I thought could be more user-friendly. Currently, the valuable information stored on the website is difficult to access (Kentucky Autism Training Center 2023).

Delphi Center for Teaching and Learning

I interviewed a representative of the Delphi Center, Rowan, who has background in disability services, although they now help to provide teaching and learning resources to UofL faculty. This individual often helps instructors and students alike by taking existing inaccessible online course content and making it more accessible. They make edits to online course content themselves to make it more accessible or support faculty to do so, in ways such as adding captioning to videos, decluttering slideshow presentations, altering text and images on virtual course content to be compatible with screen readers and similar technologies, and many more applications of their knowledge of digital accessibility.

In our interview, they stated that they have two primary forms of assistance: proactive and reactive. Proactively, they can help to make course content accessible for instructors that are looking to be more inclusive, host workshops that include brief trainings regarding virtual learning, and have important conversations about accessibility with university faculty. Reactively, when an instructor has a student enroll in their class with a particular kind of disability that limits their access to existing course content, that instructor can reach out to Rowan to request assistance with the conversion of the relevant online instructional items into accessible content. Rowan does not interact directly with students, as they offer resources for the teaching and instructional side of things, however I would say that this person positively impacts disabled students indirectly through the distribution of their resources and knowledge.

UofL's Delphi Center for Teaching and Learning houses workshops and other resources on a variety of topics for instructors looking to engage in learning themselves to strengthen instructional theories and practices (Delphi Center for Teaching and Learning 2023). They have an online training course, Delphi U, which the representative referred to as a "crash course" in virtual learning pedagogies and praxis. Delphi U is offered in three ways: a 4 day in-person workshop, an 8-week synchronous online course, and an asynchronous, self-paced online course. These workshops are available for free to all UofL employees and students. In-person workshops have still not resumed after their suspension for the COVID pandemic, though this has allowed the Delphi Center to make more of a concentrated effort toward the upkeep and expansion of conveniently accessible online resources (Delphi Center for Teaching and Learning 2023).

Due to the similarities between Rowan's responsibilities and those of the DRC, they often interact and work very closely with one another, though their spheres of operation are distinct. The Delphi Center and DRC share some resources with one another and collaborate when it is useful, but they primarily stick to their particular areas of expertise to keep functions smooth and organized, as Rowan explained.

The hasty switch to virtual learning at the onset of the COVID pandemic was particularly difficult for Rowan as the primary resource for UofL faculty looking to make their online content more accessible. When the University switched to virtual learning during that period, faculty and staff had less than two weeks to prepare and make their content accessible online. They described the process as "like triage mode", trying to prioritize and delegate while quickly addressing the needs of the entire University community as they went through the process of creating an online course for the first time. Rowan said that this process would have taken around a year under normal circumstances.

Instructors

The faculty I interviewed for this research came from a variety of professional backgrounds. Dan is a seasoned instructor in Engineering, Sam is a professor in hard sciences, and Stephanie and Scott are in the social sciences. When asked what it is like to be an instructor at UofL, every single faculty member that I interviewed had an overwhelmingly positive opinion of their job and their students. They all expressed genuine care for their students and a love for teaching. Their answers to interview questions were consistently positively student-centered, demonstrating that they are invested in their students' experiences, wellbeing, and success. More than one faculty member said that they believe UofL is a uniquely accepting and compassionate community. From the narratives of stakeholders in their interviews, there is an overall feeling that UofL's campus is accepting, inclusive, and understanding of our students.

Making Accommodations

When asked about what efforts faculty made to be inclusive of students with disabilities, the most common experience that faculty described was making accommodations in their courses based on documentation sent to them by the student or the DRC. On accommodations, social sciences faculty member Stephanie said,

> "I can tell you how it usually takes place in my classes: Students reach out via email and let me know ahead of class. Usually, especially for my online classes that they have certain challenges that they want to work through in the class, and they have certain learning capabilities that they want to ensure they get the fullest experience out of the classroom. I usually read through the document they attach, and I always do a check back in just to see, you know sometimes those can feel a little standardized. I encourage them to look at my syllabus and to look at the Blackboard module I created and all the information I put in Blackboard. And then I ask them, more specifically, if there's anything they see in the class structure or schedule information that we can talk through and work through."

Similarly, most of the accommodations that students need from Scott are extra time on exams and assignments, though as a practice he is intentional in not over-testing students and to only do it sparingly and constructively. Dan, Bailey, and Sam also referenced exam accommodations as a request that they often receive.

Bailey's answers were thoughtful and compassionate toward UofL students. When I asked Bailey about what efforts they made to be inclusive of disabled students in both their previous role and their current one, they answered frankly, "Probably not enough." This shows a willingness to grow and learn, a skill that I think everyone, especially instructors, can benefit from. No one is perfect and to admit that one's actions could be better and more intentional takes courage and humility.

> "I would try to make myself as accessible as possible to the students and hope that if they had some sort of disability that they wanted to disclose to me, if it wasn't apparent, that they would feel comfortable doing that. And we could talk about how best to navigate that and get them whatever they needed in other courses, as well. And that happened occasionally. We would occasionally have students who are on the autism spectrum. In terms of physical disabilities, I didn't have a whole lot of students that fit into that, at least that were apparent to me or brought to my attention. I had a few who had some mobility issues."

This quote from Bailey demonstrates their intention to be accessible and inclusive, and also aware of the wellbeing of all of their students. That this person was thinking about it and processing it when they were still teaching enough to bring it up in our recent conversation indicates that they were making efforts to be inclusive of disabled students in their classes at that time, and still think about those experiences today.

Experiences with E-Learning from Instructors

Scott, adjunct faculty in Arts and Sciences, enjoys teaching so much that he sought it out as a second career when he retired from his first unrelated and more monetarily successful career. When asked about his experience with teaching online, he said that he actually teaches most of his courses in VLEs nowadays. Even though it is not the first choice most instructors would pick, he teaches online because he is flexible in the mode of courses he can teach, capable of navigating the appropriate computer programs and communications, and happy to be teaching in general.

Scott taught some hybrid courses during COVID which he said were very difficult because they were hastily prepared under emergency circumstances and were confusing and uncomfortable to learn under the stress of the pandemic for both instructors and students. This is an experience that Rowan of the Delphi Center spoke about as well.

Another instructor, Stephanie, spoke brightly about her students and their commitment to learning, eagerly praising their talents during our conversation. She said of COVID and virtual learning:

> “I think we all had to pivot quite a bit for the shift [regarding] COVID, but I had great classes during that time… There [were] students that seemed more able to or wanting to engage. Maybe they just had different levels of comfort in that situation, so I'd say overall it was not a bad experience for me, but I certainly also appreciate the ability to bring more applied and engaged hands-on kind of learning... So, I saw benefits from both experiences, and I don't think the learning experience necessarily lacked anything during the online portion. That's why I think I've continued to teach an online class because I also see that there's a big population of the student body that needs that and deserves that kind of course, even if it's not in the classroom.”

Scott often teaches online so many spatial components of accommodations do not apply to his classes such as a quiet place to take exams or sitting near the front of the classroom. These are things that the student is responsible for figuring out themselves or with the assistance of the DRC. The biggest efforts he personally makes for disabled students are trying to best honor their accommodations and making himself accessible by responding to email correspondence within 24-48 hours.

Stephanie says of one of her introductory courses that she teaches online: “In terms of structure, I make it self-paced. I will open up modules for two weeks at a time. Each module includes a lecture that I've [recorded], the lecture that I've written on slides that can be read, and then videos and other articles that kind of connect to those same topics. And then I have a discussion board every other module where students offer opinions and reflect on material. And then I have written assignments where students process the information from the class or from the module and use it to answer more specific questions or read an article and reflect on that.” Through the seven modules, she offers a variety of learning methods and a wider period of time than most courses offer to pace oneself through the course, within a two-week span.

Stephanie also tries to incorporate a variety of educational media and methods. She thinks that the smaller class sizes of her courses and UofL in particular are likely useful for disabled students because they are closer to the professor, both physically in the classroom and socially, and that the instructor is able to devote more time to each individual student’s needs.

Another professor, Dan, said regarding VLEs that he cannot verify that the physical learning space is conducive to knowledge retention and is unable to be sure that there are no preventable barriers to learning in that student’s space. Therefore, he prefers in-person learning just because he has more control over the physical and social learning space and can better-guarantee a positive learning experience.

Bailey, the administrator and faculty member, suggests that the development and expansion of virtual learning opportunities also expands the accessibility of course content. This aligns with Rowan’s experiences in their role as a resource for developing and distributing accessible online content. Though there is scholarship that argues that VLEs are *not* any more accessible than traditional classrooms (Lee 2017), other scholarship contends that the expansion of VLEs *can* increase accessibility. (McAvinia 2016; Moreira 2016).

While many factors influence accessibility, the capacity of individuals to express their agency unhindered is key to accessibility and, thus, expanding the options available to students and faculty increases their opportunities to exercise agency over their own learning or teaching, respectively. As long as there is an option that feels accessible to the learner and teacher, whether that is in-person or virtually, that is what fosters accessibility and inclusivity (Ahearn 2001; Eyler 2018; Weimer 2013).

Identifying Resources for Students with Disabilities

Some students stated that a lack of understanding of most disabilities from their peers, faculty, and staff led to feelings of exclusion and isolation, though some student interviewees did say that this exclusion is likely not intentional. This could be mitigated if students and, more importantly, faculty and staff are required to take sensitivity and awareness trainings regarding common disabilities and how to independently learn more about the needs of students with various disabilities. Students and teachers alike both express a frustration with the lack of awareness of the resources available to students with disabilities at UofL. Some students feel that there is no support for disabled students at all, some think that there likely are resources and that they are just unsure of how to access them, and some students know that there are resources on campus for students with disabilities, but that they are not utilized as often as they could be due to a lack of awareness.

Scott, like some of the students I spoke to, wishes that instructors were given a list of resources for disabled students to help connect them with the assistance that is best for them. Having to seek them out is an extra step for instructors that is not easy and can be discouraging, so it would be helpful for them to have something like that on-hand. “We can't help them with what we don't know,” as he said. Seeking out resources that they are not sure exist is an obstacle for instructors trying to help their students and for students that are trying to seek help for themselves.

Stephanie, faculty in Arts and Sciences, wishes that mental health resources were more available and accessible on campus. She said that it would be helpful to know who to call or where to send a student to get help if they needed it urgently. Stephanie said about a particular student she was concerned for, “I wanted to know that my student got to the Student Health Center. I wanted to know that they were spoken to. I don't know how (or) if that could have ever happened, I know there's privacy issues with that.” She expressed the desire to connect students with resources that could benefit their learning and personal wellbeing, particularly regarding mental health.

Stephanie says that she hopes that all teachers remember what it was like to be a student and attempt to remain in-tune with that and sympathetic to their students. “It's a high-pressure time for students, especially for this generation, I would say.” She says that she pays attention to the details; even the timing of students' emails can help her to get a sense of their needs and drive to succeed. She says that some students will reach out as early as June, which demonstrates that they really want to be as well-prepared as possible. She does her best to be available to students in the way that is most convenient for them, whether that is on campus or online.

Bailey says of UofL faculty: "I think that we have faculty and staff who are student-centered and who are well-intentioned, and who are interested in helping the students become all that they can be. And that's for all students." Faculty are not innately able to accommodate every student, but Bailey believes that most faculty at UofL are eager to seek out logical and empathetic solutions for each of their students when necessary. They want to know how to best support their students, even when they need assistance in doing so.

An instructor of hard sciences, Sam has interacted with the DRC and did a training hosted by the Delphi Center with the Kentucky Autism Center. Trainings are offered sometimes, but not required. Utilizing what they have learned from these resources, Sam attempts to be inclusive in their classroom by listing disability policies in the syllabus, not using italics or underline in text presentations, being careful about what colors are used in illustrations and diagrams, using fonts without serifs, utilizing other symbols and images besides use of color, utilizing organized tables to show data, being aware of compatibility with screen readers, etc. A student's sensitivity to color and text such as color-blindness or dyslexia can be particularly impactful in courses regarding scientific structures or diagrams that are mapped with color or labelled. Serifs and unnecessary clutter can be detrimental to the readability and accessibility of presentation slides and other visual materials because they can be easily misread by both human eyes and electronic resources like screen-readers.

Another faculty member, Dan, said this of what he learned from a Delphi accessibility training: “There are certain things that I wasn't aware of in the past, which is the colors that you pick when you create your slides, they may look fancy and colorful… but to some people they become very hard to read, the contrast is not right.” He says that through his relationship with the Delphi Center, he learned what tools were available to him as an instructor. “For instance, when I upload my lecture and my slides, I test them and make sure that they are actually [accessible] through Blackboard. Blackboard has tools that actually will tell you – will score how suitable your slides are for the visually impaired student and they give you the appropriate tools and you continue to update and modify your slides to cover all figures or objects that need to be described and things like that.”

The Speed School also offers optional trainings in conjunction with KATC to faculty in Engineering in regard to autistic students because, according to the faculty I spoke with, many of the students with disabilities in their school are autistic.

Genuine Care for Students’ Success

In response to interview questions, all stakeholders spoke with conviction about their dedication to supporting students and their desire for all students to be successful. This conviction was most evident with the instructors, who spoke about bring thrilled to interact with students on a regular basis. Although some students felt that particular instructors did not always have their best interests in mind, the faculty that I interviewed all seemed genuinely interested in the success of their students. Faculty interviewees spoke highly about all of their students, even when some were more challenging to teach than others. All stakeholders that interacted directly with students expressed a true hope that each of their students felt supported.

When asked what it is like to teach at UofL, Stephanie said, “It's a really positive experience. I get a lot of fulfillment out of class times with my students because they seem engaged, they seem excited to be learning. Some of them are first generation, not all of them.” Similarly, Scott said, “I think, since we're in the service business, we should be serving our students or trying to help them.” Though he says he could see how some other – more “competitive” – disciplines might have different expectations or values.

When asked what he thought might go well for disabled students at UofL, one instructor said, “My sense of it is with the DRC resources for students, I would think they would feel pretty confident that they have the support of the institution for being there, for achieving their academic goals and getting proper levels of help.” This seems to be the general opinion of faculty, that since the DRC exists and maintains contact with instructors and students alike, disabled students should feel well-supported. However, considering the student data I present in the next chapter, there is some incongruity between how stakeholders expect students should feel, and how students actually feel. It seems like the faculty I interviewed are responsive to students’ needs and to employing DRC accommodations, and thus those faculty may be more likely to see students succeeding in using their accommodations and feeling better-supported overall. Students I interviewed, however, are experiencing a wider cross-section of course instruction at

UofL than instructors and thus likely have a broader set of experiences - including negative ones. I delve into this array of student experiences more thoroughly in the next chapter.

Instructors' Concerns

A concern voiced by half of the faculty I interviewed is the general “bugginess” of the VLE programs that they must utilize for course content, such as Blackboard, Panopto, and Respondus (LockDown Browser and Respondus Monitor). Faculty who use these programs felt that they interact poorly with each other and that they make carryover between classes and semesters complicated. Stephanie said that would really help her to be more accessible to students is improving the interface for videos on Blackboard, saying of the current system that “it's making video access difficult for students.”

The classes Sam usually teaches explore the hard sciences and require participation in labs. This conversation led us to their biggest concern: that labs are not ADA compliant or adequately accessible. Aisles between tables are too narrow, tables are too high, mirrors are not available to see tabletops, sinks aren’t low enough, and so on, amounting to the conclusion that lab rooms are not wheelchair accessible at all. For students with physical disabilities, these labs spaces are incredibly hostile and actively prevent students from accessing the education that they are entitled to. Sam and their colleagues have considered adaptable lab equipment such as beakers with handles, special goggles for lab eye protection, use of mirrors to see tabletops from a low vantage point.

On the inaccessibility of some learning facilities, Bailey said, “We do have some facilities on campus that are not as physically accessible as they should be. And I wonder how that affects the instruction right? I mean, I wonder if that or how that affects the opportunities that some of the students are getting.” Dan said on the same topic that, as an instructor, he unfortunately cannot control that old buildings are sometimes not ADA compliant or are inaccessible to some physically disabled students. This makes part of his job more difficult: the responsibility to make sure the spaces he teaches in are accessible and conducive to a positive learning experience.

Dan has been teaching for a long time now and our interview happened to take place within the immediate days after the policy to be race-inclusive in college admissions via Affirmative Action was overturned by the Supreme Court in the case of Students for Fair Admissions v. Harvard, No. 20–1199. He says of this decision:

> “The thing that impacts the administration a lot more than it impacts me personally… is the ability to recruit students from varying backgrounds and to make sure that the way we treat students is equitable … So, we're talking about the Supreme Court’s latest decision, [one of] the things that they talk about nowadays is the legacy admission. I don't think that any factor should be taken into account that gives advantage to one class over the other… If we cannot consider the hardships that are due to an individual being brought up in a disadvantaged class, if we cannot give that student a head start [to] level the playing field, then we should not give those people who come from alumni or money or prestige a leg up over those students.

I imagine that Dan’s sentiments speak for many of his colleagues as well, who truly want the best for their students, though have limited agency to exercise over more powerful institutional mechanisms.

Summary of Stakeholder Perspectives

The experiences of faculty and staff that facilitate the learning experiences of students at the University of Louisville align in some very interesting ways. Some of these commonalities highlighted in this chapter include limits in knowledge of rapidly changing technology, the existing power dynamics between student, teacher, and institution, and a feeling of sincere empathy from faculty for their students. Stakeholders seem to largely share the collective experience of wanting to help their students learn and excel, but either are unsure how to further help or are limited by finite institutional or personal resources. The data collected from institutional stakeholders suggests a cultural landscape heavy on emotional, mental, and practical labor for stakeholders at the University of Louisville, though this does not seem to diminish stakeholders' eagerness to fully support students at the institution. From the stakeholder perspective, there are feelings of wishing that the institution as a governing body were more supportive of both students and stakeholders as agents of learning and community-building for the institution. Stakeholders express a desire for more accessible resources for both students and stakeholders without further adding to the existing labor of students and their primary institutional stakeholders. In the following chapter, I will describe the relevant experiences of students with disabilities at the University of Louisville that I have gathered through qualitative data collection.

CHAPTER THREE: EXPERIENCES OF STUDENTS WITH DISABILITIES

There are seven total students who participated in this research: four undergraduate students and three graduate students. The undergraduate students include Thomas, Jordan, Katrina, and Autumn. Thomas, a white male student, just received his degree in the social sciences shortly after we spoke and is considering graduate programs out-of-state in the same discipline. Jordan, genderfluid and white, also graduated just after our interview with a degree in social sciences and is a knowledgeable advocate for fellow students with disabilities. Katrina is a white, female engineering student at the J.B. Speed School of Engineering. Autumn, who identifies as an Arab female, is pursuing a dual degree in the health sciences and has a career in health services. Of the undergraduate students I interviewed, only Autumn and Katrina utilize the DRC for accommodations. Though the other two were aware of DRC services, Thomas did not feel that he could benefit from them, and Jordan does not have a formal medical diagnosis, so they do not have access to DRC assistance. All undergraduate student interviewees were in their early 20s besides Autumn, who was 19 years old at the time of our interview.

Of the three graduate student participants, all of them utilize accommodations through the DRC. Diane is a biracial Black woman pursuing a graduate degree in social sciences in her late 40s. August, a white autogender student also in their 40s, is working on a health sciences degree, which is intrinsically tied to their experiences with disability and advocacy. Marissa, a 24-year-old female African American and Indigenous American, is a little more than halfway through a dual degree in applied social sciences.

Throughout this chapter, I will describe their experiences as students with disabilities at the University of Louisville as they relate to the following categories, which were informed by the data collected through this research: Accommodations through the Disability Resource Center, Self-Advocacy, Intentional Inaccessibility and Ableism, “Othering” Students with Disabilities, Students’ Experience with Online Learning, Impact of Disability Upon Learning Experiences, Disabled Identity, and Lack of Community Space for Students with Disabilities.

Accommodations through the Disability Resource Center

From the narratives of students utilizing the Disability Resource Center, there seem to be wide range of opinions on the helpfulness of the DRC. Students described unexplained gaps or rigid boundaries in the assistance that they can offer to students with disabilities. What or who limits the powers of the DRC? These restrictions in assistance from the institution lead to mixed opinions from the students that have observed them. Most participants - stakeholders and students alike - said that instructors and staff are supportive, and that the DRC is helpful in what they do. However, they noted that there is some disconnect with inclusion, though it is hard for them to identify specifically. There is a feeling of the “ball being dropped” and the responsibility tossed around like a “hot potato”, but it wasn’t clear by whom. I think that this ambiguous, omnipresent chasm emerges from the intentional institutional and larger societal design of rigid boundaries in which members of marginalized social groups, like people with disabilities, are able to act and exercise agency.

August, Katrina, and Diane all specifically expressed frustration with the limited scope of accommodations provided by the DRC and a lack of consistency in communication regarding accommodation options. For example, Diane and August believed that students could attend class virtually with a formal DRC accommodation. However, when I sought out assistance on that topic from the DRC during the end of my undergraduate studies and the beginning of my graduate studies, I was told that instructors could not be made to teach online because the class was not virtual initially and could not be made virtual. I could ask instructors if they would be willing to do so, and so I did. Some of my teachers were more willing to do this than others. Diane spoke to a similar experience: half of her instructors were willing to, and the other half were not. This is just one snippet of difficulty, and within the pages below reside a few more examples.

August, a student in health sciences, was eager to speak about their experiences as a student with disabilities at UofL, indicated by their tone in emails and the excitedness with which they spoke in our interview. Their black baseball cap bobs up and down as they nod in response to something I said, or perhaps their own thoughts on the subject, eyes bright as they excitedly describe a particular thought. Less excitedly, they describe the process to get course material videos and recorded lectures captioned as being very difficult and wonders why they have to defend their disabilities in order to receive accessible content. They say, “Even if somebody didn't have limitations like the hearing challenges, why would they go to their professor and say, ‘Will you please go out of your way to do closed captioning?’ They wouldn't take time out of their day to ask.” This is a great point, which argues for the expansion of accessible resources without worrying about people taking advantage of them. August’s testimony suggests that those who do not need accommodations would not go through the trouble to request them.

Though the DRC is meant to mitigate uncomfortable experiences for students with disabilities, not all students who utilize the DRC are guaranteed to experience less difficulty. When a student is met with resistance from an instructor regarding a formal accommodation issued by the DRC, an advocate from the DRC will offer to meet with the student and the instructor to work out the situation. However, interviews with students suggest that there is a general fear of confrontation when a student considered this kind of situation, whether real or imagined, even if there were a DRC advocate present. Students will often decide not press the issue past that point in order to avoid confrontation altogether. Though perhaps not an effective way of getting someone’s needs met, there are real power differentials between students and faculty, and thus these fears are not unfounded.

One engineering student, Katrina, stated that some of her professors were unwilling to make any accommodations at all, even though she had DRC documentation requiring access to them. She felt that she had to “argue” with some of them to defend both her accommodations and her disabilities, which in the end she felt was not worth the fight. One example she gave was that one of her classes had weekly mandatory quizzes, but her disability impacts her ability to attend classes all the time, something she does have an accommodation for from the DRC. The instructor of that course allows one makeup quiz per semester, which once used is gone. Katrina spoke with the DRC about forcing the issue to be able to make up the other quizzes when her disability prevented her from attending, but it would have required a meeting with the instructor, a DRC representative, and Katrina herself, a daunting task when this instructor had demonstrated what felt like a lack of understanding of the impact of Katrina’s disability. Because of that situation, among others impacted by her disability, Katrina struggled academically and was flagged by the Student Financial Aid Office for unsatisfactory academic progress, so she had to file an SAP (satisfactory academic progress) appeal to remain enrolled. She described the subsequent self-correcting process as complicated, especially during accelerated summer courses.

Being disabled comes with a plethora of social side effects, one of which is the feeling of having to defend your disability to others and to yourself. It can be a difficult and invalidating experience that occurs directly or indirectly, ranging from a blatant question or insult to the way someone looks at you or speaks to you. Some students spoke of a general feeling of being infantilized and overgeneralized as soon as someone finds out about their diagnosis. For example, a student with hearing loss disclosed that information to a peer they had been in class with for a while, and all of a sudden, that other student started speaking unreasonably loudly and simplistically, as if they had not been carrying on a conversation before they were aware of the disability. This does not encourage us to seek out moments of confrontation; even though they can sometimes be transformative, or at least productive, they can also be dehumanizing and volatile.

Diane had an experience similar to Katrina regarding an accommodation that half of her instructors would not implement. Both Diane and Katrina were offered a meeting with their instructor and a DRC representative for support and accountability, but the students expressed that this kind of direct confrontation can be stressful and demoralizing or even degrading and dehumanizing when the individual invalidates their experiences and needs. When disabled people are asked to defend our needs and experiences in small ways day-to-day, we are inundated with the narrative that our experience is invalid. When we know that an experience like this might be coming, it is not only stressful in the moment but can induce stress and anxiety leading up to it.

Diane stated that the semester during which we interviewed was tough because of those instructors that did not provide accommodations. It was so taxing because she should have gotten the accommodations and had put in all the work to get them: she got documentation from doctors and hospitals, then went through the DRC's appropriate channels to request accommodation letters, and then delivered those letters to her instructors. She said that the accommodation for deadline extensions was not offered, even though she was hospitalized and receiving transfusions routinely throughout the semester. Diane was told that she could attend classes virtually, especially during critical moments around hospitalizations and transfusions, and then her instructors informed her that they were not willing to do that. Ultimately, she ended up having to withdraw from one of the classes because she said that she was promised accommodations from the DRC to allow her to participate that never came through from the instructor.

Diane says that this made her life more difficult than it already was with her ongoing health difficulties, having to prepare for and participate in a class when she could attend, and then to be told that they would not be willing to provide the accommodations to allow her completion of the course. It made her feel like all the work she did was not enough and that faculty were not willing to help at all. She says, "I don't think people with disabilities say, ‘I want more…’ I just want you to be fair to me. That’s it. Just treat me fairly… I think other people look at persons who have disabilities as, ‘You want me to give you the world, you want me to do special accommodations. You want me to do extra because you're disabled.’ I don't want you to do extra. I just want you to help me to assist when I have these episodes. When I am unable to do something because I'm having an episode.”

Another student, Marissa, has experienced similar frustrations, explaining that she got partway through the semester and realized that her accommodations were not being addressed. She went to the teacher to talk about it, but the teacher acted like Marissa had never sent the letter and had difficulty believing her. Marissa and I wonder if this is perhaps because her illness is invisible? Indeed, several interviewees with invisible disabilities feel like they have a harder time being taken seriously. Ultimately, though, Marissa said that she feels she has been treated as well as any student without disabilities and believes that a world is emerging in which the discussion around mental illness and disability becomes easier to have, and with that comes an opportunity for everyone to learn about experiences different from our own.

Though I have led with a couple of negative experiences because some of those were more powerful stories, plenty of students have had positive experiences with the DRC as well. Some students felt that the DRC was incredibly helpful, completely met their needs, and even went above and beyond for them. Though she had some negative experiences as well, Marissa, went so far as to say that her DRC coordinator has been like a second therapist to her, helping her to identify and mitigate triggers specific to her learning experience.

> “That [DRC] coordinator really helped me identify like where my triggers were with like… public speaking and speaking in classrooms. So, I know like I'm more of an online taker as opposed to like an in-person class. She kinda is like my second therapist because like, the way that she thinks and her perspective, it allows you to like, think and reflect on yourself and your understanding of your own disability, because sometimes it's hard to understand yourself and like why you're in this predicament and everything that just encompasses your disability.”

Marissa explained that in person classes can be overstimulating and triggering at times, whereas through virtual learning she can be in her own safe space and fidget around comfortably without worrying about disturbing others, or, in a particularly difficult moment, could turn the camera off. The teaching style of traditional, in-person learning is more attractive to her (i.e. lectures), but the practical use of virtual learning spaces is also tremendously valuable to her. Online courses can involve more work in some ways, as it requires the student to motivate themselves, regulate their own schedule, and maintain higher levels of responsibility for the time-management of schoolwork.

Pursuing a dual graduate degree in applied social sciences was difficult enough, but Marissa was also struggling with bipolar disorder, severe depression, and anxiety when she began her graduate studies. Her mental health at times was a serious detriment to her academic work, especially when she was still trying to figure out what she was feeling in order to receive a diagnosis, or to even know that one was necessary.

After she was able to work through the simultaneous initial adjustment to graduate school and the exacerbating impacts of COVID, she was able to process her mental health needs. This began by meeting with her DRC coordinator and discussing difficulties with her mental health and studies. Her coordinator helped to identify triggers specific to learning environments and find ways to work around them. Realizing that some features of the social landscape of higher education, such as public speaking or being called on during class, are not conducive to her learning because they negatively impact her health, has helped her to learn better and maintain her mental health – and thus, overall health – more easily. In fact, school was one of the driving factors that encouraged her to push through the worst of her mental health days. She said that it gave her a reason to get out of bed in the morning and maintain some sort of routine.

A few participants mentioned difficulty with the tedious paperwork processes of the DRC and Financial Aid in general terms, such as August, who stated that it is a struggle to have to resubmit their accommodation letters and paperwork every semester when their disabilities and accommodation needs have not changed. They suggest that this process places the burden on the person with the disabilities, adding more to their plate as a stipulation and an obstacle to accommodations, an experience that is supported by scholarship on the topic (Bruce and Aylward 2021).

Not all students with disabilities utilize the DRC. One such student, Thomas, did not feel that they would personally benefit from utilizing the accommodations that the DRC offers. Perhaps a part of this as well is that this student described their father as a "pull yourself up by your bootstraps" kind of individual, the impact of which may have deterred this student from taking help when offered. I can only speculate as to whether or not they may have benefitted from assistance from the DRC. This individual is on medication for their anxiety and suggested that it is common for their college peers to be on medication for their mental health or to speak casually about their mental health. Thomas used to be on medication for ADHD in the past, though they felt that the side effects were too uncomfortable and chose to focus on other ways to mitigate the impacts of their ADHD. Thomas now manages most of their symptoms without medication, again leading them to believe that they do not need assistance.

Choice is not the only factor for some students who could benefit from DRC accommodations, but do not meet documentation requirements. Some students cannot access the DRC due to a lack of formal diagnosis, and Jordan is one of those students. Jordan is social sciences student who was wrapping up their undergraduate degree when we interviewed and has managed the symptoms of their self-diagnosed disability without the assistance of medical care or DRC accommodations. Fibromyalgia runs in their family and though they do experience many of the symptoms, they currently do not have access to the healthcare that they would need to get a diagnosis. As such, they are ineligible to utilize DRC accommodations, though their disability is disabling enough that they need to utilize mobility assistance intermittently when their symptoms are particularly debilitating.

Self-Advocacy

Not only can it be an obstacle for disabled students to reach out to someone for help or to admit help that is needed, but some students do not know where to get assistance (Bruce and Aylward 2021). Many of the students that I spoke to utilize the DRC because, in part, I recruited through a DRC emailing list, meaning that my participants were potentially skewed towards those students using the DRC as those are the students who make up that mailing list. Some participants, such as Marissa, know that there are resources on campus for disabled students but think that they are not taken advantage of because students might not be aware of them. As a participant in student leadership who sought out this information and engaged in many informative conversations about mental health with administrators and faculty, Marissa speaks with authority on this topic.

It is difficult to learn to self-advocate and this continues to be a challenging process to engage in. One student, August, had experience advocating for other disabled people before they discovered that they were disabled themselves, and says the experience of having to advocate for oneself is a much different and more difficult one than to advocate for others (Bruce and Aylward 2021).

Participants August and Diane both stated in their interviews that, as older students returning to school after a former career, they probably have more resiliency and tenacity than younger, less experienced students likely do. This makes them good advocates for themselves and others but leaves them concerned for other students with disabilities that are not able to advocate for themselves as effectively. August stated, “I have a lot of tenacity and I have a lot of ability to seek out the information. I don't know that really young students have that same capacity.”

Diane said that she worries for younger students with disabilities that “do not know the protocols of how to advocate for themselves” when their needs are not being met. “That's what angers me more than you think, because I know there's people out there just like me – [that have] been treated just like me – but just do not know how to maneuver the system and advocate for themselves. That's the most disheartening thing ever, that I know there's people out there like me. I know there is. I know there’s people right now that some instructor has given them hell.”

On the flip side, Katrina suggested that the social aspect of being disabled is relatively easier in college, and that most of her peers and professors are understanding of her disabilities. Unlike most of our disabled adult peers, she was diagnosed young and thus has been advocating for herself since she was in 5th grade. This shows the breadth of variability in the experiences of people with disabilities, dependent upon both symptoms of an individual's particular disability and perhaps how long they have had a formal diagnosis for it, if at all.

Inaccessibility and Ableism

"The whole world is designed to not meet our needs." This quote from August has really stuck out to me over the months that I have been doing this research. This participant did not say that the world is not designed to meet our needs, they say that the whole world is *designed to not* meet our needs, which implies an intention to the form and function of the world around us. This suggests an intentional focus on architecture and other structures that are intentionally restrictive and inaccessible. This also applies to structural obstacles that are not so visible as architecture, such as institutional design.

Institutional designs that intentionally exclude students can be seen an example of hostile design. A more literal example of hostile design could be something such as public benches with railings that block people from lying down on them to prevent houseless people from sleeping there (Rosenberger 2020). To extend the category of hostile design, consider this example: We are all used to seeing stairs in public spaces, but do we ever consider why stairs are so common? It is an intentional choice to put stairs somewhere instead of a ramp or another means of going up or down levels. Just because it is the norm for stairs to exist does not mean that ramps are not just as easy to build or cost any more. Instead, it is because as a society we are used to seeing stairs and walking up and down them without a second thought. Those of us that struggle to catch their breath or grimace with every crunch of a joint as your weight shifts uncomfortably up the steps are outliers. Truthfully, we stifle those agonizing breaths and grimaces so that no one sees how deeply we struggle. Hostile and inaccessible design is as relevant to institutional structures as it is to physical ones.

One student, Jordan, who I mentioned earlier, described the phenomenon of being socialized to do things the way that the people around you are doing them in order to appear "normal”, even if it causes you physical pain - such as taking the stairs, pretending to not be in pain, not utilizing a mobility aid, and other experiences in public spaces. They describe this experience as almost punishing yourself for experiencing the discomfort in the first place when everyone around you seems to have no issue with the task. This can have a seriously debilitating impact on an individual's mental health, their perception of the world around them, and how others perceive them.

Jordan’s own experiences with disability encouraged them to work for the DRC and participate in their mentorship program, though it went defunct during COVID and has not since been revived. Jordan has utilized the Counseling Center at the University and, though I did not ask specifically about students’ utilization of the Counseling Center during the interviews, only two students mentioned it: Jordan and Marissa. Marissa says about the UofL Counseling Center: “Even though the wait time is a little terrible, the quality of the people is good. So at least I can say that, that's really the biggest reason I've stayed here, is because I felt like my mental health has actually been seen and heard here."

August was in a class during which the teacher began making fun of a particular mental illness by making gross assumptions and generalizations about the kind of objectionable individual they would expect to have that kind of mental illness. In their own words:

> "Neurotypical folks who don't take into consideration the lived experiences of people who aren't neurotypical. Just the other day, [in] my psych class, you know, we were covering personality disorders. And [the instructor] was talking about - which one was it? Doesn't even matter which one it was, but the professor was giving examples… And it wasn't schizophrenic… It was like – I don't think it was borderline personality, but it was something along there – but she made the comparison that she thinks of that type of person as being the Dungeons and Dragons person, the one that goes into their basement and sits down and plays Dungeons and Dragons. And then she's kept elaborating on it. And then she had this slide. That was a picture, it was a like an illustration that was supposed to depict what a person with this personality disorder would look like, right? And everybody in the class was just laughing and joining… All of them making fun, and it didn't just stop with that one slide and that one personality disorder, it kept going."

Even though it was not the disability that this particular student had, the experience of witnessing peers and their instructor making fun of mental illness made them feel othered and extremely disappointed in both the individuals perpetrating the judgement and the institution for allowing this to occur. They felt that they could have been judged just as harshly and unfairly for things beyond their control. They said they would like to have picked up their things and stormed out of the classroom, but were worried that, since the whole classroom knew they are autistic, they would be exemplifying the stereotype of autistic people being too sensitive.

August also described another experience of being in a different health-related course and being shown slides describing various disabilities, and the one on autism just showed a list of generalizations and stereotypes. Having a high expectation of the courses related to their major, they were particularly disappointed, knowing that this is not their experience with autism and that the slide showed opinions that are not backed by any reputable scholarship.

Students' Experiences with Online Learning

Some students, such as August and Katrina, who do not personally perform well in online classes still believe that they should be an option, especially for students with disabilities that impact their ability to consistently come to class in-person. One student said that they wished their instructors were better trained on technology. The student explained that they do not feel like it is the teacher's fault that they do not know how to do certain things, but that the university should provide training for teachers looking to hone their technology skills and knowledge.

Katrina said that she has a hard time with virtual learning because it requires her to merge her home and school life, which has not been healthy for her in the past. Marissa said something similar, but both of them agreed that VLEs are a good option to have when they need to utilize it.

A faculty member that I interviewed, Scott, said something along the same lines: that he cannot help with what he does not know. Though he was speaking about not knowing how to assist his students with disabilities if they do not come to him with their concerns, I think that this can also be applied in a more general sense. Instructors have to know what their students are going through to be able to assist them, so what can be done to strengthen the line of communication between teachers and their students, both in VLEs and traditional classrooms?

Though these students did not personally perform their best in VLEs, they would still like the option to participate virtually, especially on low energy days. Some students suggested that there should be routine meetings for them to be effective, suggesting that synchronous online courses would be the preferable option. I will reference the distinction between synchronous and asynchronous throughout my writings. Synchronous courses have regular meeting times during which the instructor and students all log into a virtual meeting platform such as Microsoft Teams or Blackboard Collaborate to participate simultaneously or collaboratively in learning activities or observe a lecture. Asynchronous learning relies on posted content that is not necessarily instantaneous or collaborative in nature, though elements of remote cooperative learning can be incorporated such as discussion boards requiring engagement with peers or assigned study groups.

This data supports the suggestion that teachers should be trained on the technology and equipment that they will need to use to make their content accessible, both in the classroom and online. That instructors do not know how to use technology or equipment is not an excuse to not make content accessible, but the pressure to seek out that information should not be on the teachers alone because the expertise and information would still be uneven between individuals. This is an experience that the instructor participants also spoke to: a true aspiration to support their students fully, but also frustration with not always knowing how to best do that.

Impact of Disability Upon Learning Experiences

Katrina has formal diagnoses of Type 1 diabetes, dysautonomia, and Hashimoto's disease, though the first two are the most "disabling" for her. She says of her disabled experience that there is "never a moment I'm not thinking about it." This means that when she is trying to do anything pertaining to learning, there is always a piece of her mind focused on her physical state. This is a self-preservation tactic that people with long-term health conditions sometimes develop to mitigate the frequency of medical emergencies. In Katrina's case, she would be constantly thinking about things like her blood sugar: How does it normally feel? Does it feel weird or unusual right now? Is my blood sugar low? Is it high? Is this a normal weird feeling or one I should be concerned about? These are the kinds of questions that permeate the minds of people with disabilities. Is the discomfort that I am currently experiencing more or less uncomfortable than usual? Should I be concerned?

Thomas spoke to his ADHD preventing him from focusing on course materials and instruction for long periods of time. August said that their autism and auditory processing disorder both keep them from participating fully socially because it can be overstimulating when too many things are going on at once or if it gets too loud, and it can also be panic inducing when they have trouble hearing or following along. August also said that autism comes with a particular set of burnout symptoms with states of severity that can heavily influence their ability to participate in daily activities. Katrina worries about her physical wellbeing when she is trying to be present in in-person classes especially, which can often distract from her learning experiences when she is in public learning spaces.

Marissa, Jordan, Diane, August, and Katrina all spoke to their wide variety of disabilities at times preventing them from consistently attending course meetings, for reasons such as pain, dangerously low immunity, immobility, inconsistent vital signs, variable blood sugar, autistic burnout, and so on. Though these experiences manifest in vastly different ways, a common set of accommodations is helpful to them: variability in attendance requirements, leniency with course deadlines, and so on. However, limiting their accommodations to a generally prescribed set may not fully address their needs, which is where a DRC coordinator would theoretically assist in finding additional resources if available, though this would require a series of events to fall perfectly in place which, as demonstrated in these pages, does not always happen.

Katrina spoke to the rigidity of the course sequence in the Speed School being particularly challenging for her as a student with disabilities. On the days that her disability is taking more of a toll on her physical and/or mental health, she suggests that there is perhaps not the same understanding or leniency that you might find in another school or discipline. The deadlines are absolute and unbending, which can come off as cold and uncaring, even though the intention behind the heavily regimented course sequence is to prepare students for the intensive field and subdisciplines of engineering. Katrina feels that the Speed School tries to “weed out” students by discouraging them and making things more difficult than they need to be. She feels that they have set nearly unattainable goals, which do not allow for accommodations under any circumstances.

Some disabilities that are not directly mental health related still have an impact on an individual's mental health because we are not performing to our expectations or feel constantly depressed or disappointed by our conditions and their impacts upon our bodies and minds. When mental health declines, our motivation for things like learning and relationships can plummet.

More than one student stated that the impacts of their disability led them to struggle in class and to be flagged as unsatisfactory by the university. Because of this, they have to file an SAP (satisfactory academic progress) appeal to remain enrolled. They describe the subsequent self-correcting process as complicated, especially when balancing studies and managing their disability.

Disabled Identity

Though I knew my student participants *should* all identify as disabled because it was a stipulation in my recruitment materials, one of the first questions I asked in all of the interviews was, "Do you identify as disabled?" In part, this was to verify that the participants met the criteria I specified, but it was also to gauge participants' relationship with disabled identity. Students often hesitated before answering or stumbled over their answer before settling on "yes". These kinds of response might reflect wider experiences or might be on account of the specific individuals I interviewed, because my sample group consisted of students with only invisible illnesses, meaning disabilities that are not usually noticeable visually.

Multiple students stated that it was difficult to identify fully with the label of “disabled”, because it requires them to view themselves in the “third person”, or through the lens of how the outside world might label them. They said that they only have their own experience(s) to consider, so it is hard to view themselves from an abstract external perspective. Autumn, Marissa, and August found it difficult to label themselves as disabled, saying it is almost like they had to consider themselves from an external or unattached perspective that, in reality, does not exist in their experiences (Dunn and Burcaw 2013). They each said that it is hard to put themselves into that hypothetical perspective to see themselves as the "disabled" person, and it seems difficult for that narrative to fit entirely with their lived experiences because it requires a point-of-view that is outside of their reality. As Marissa said, “It's taboo, that with disabilities, not all are visible and so it's been very tricky for me to actually see myself and label that as disabled. But I label myself as to say, well, because it limits myself and limits my activities on a daily basis. So that's the only reason why I would identify as disabled.”

The kind of disability someone experiences may also have an impact on the extent to which that individual sees themselves as disabled. Participants mentioned this in tandem with almost not feeling disabled *enough* to an external observer. My data is limited by the sample group’s disabilities consisting only of invisible illness diagnoses, so I cannot assert whether broader data would support this idea or not. However, I think it is important to consider the topic because student participants mentioned this experience explicitly. Two students, August and Diane, both wondered aloud if a person with more clearly visible disabilities would have to justify and defend their experiences so consistently to others who attempt to undermine them.

Lack of Community Space for Students with Disabilities

Some students do not feel that there are any concerted efforts on campus to be inclusive of disabled students. August suggested that there should be a place where students with disabilities can go, besides the Disability Resource Center, that fosters community between disabled students and the disability advocates and resources on campus. Like August, Marissa thinks there should be a place for disabled students to go when overstimulated, but she currently utilizes the Cultural and Equity Center for this purpose. “They’re like LGBTQ+ advisors, African American advisors, women advisors. So, I’ve never felt not comfortable to talk to them about any problem I’ve had.”

The concept of a Disability Community Center is a compelling idea, even if it was just a small room in the Student Activities Center, the Cultural and Equity Center, or another accessible communal building that has seating and the capacity for small meetings. It could be a gathering space, or a quiet, relaxing space without overwhelming stimuli for students on campus. It could hold advocacy and informational meetings along with other community-building events. The lack of such a space on campus leads August to wonder: “Where's my community? Where are my advocates? Who do I turn to?”

The entirety of the participant data that I have collected through this research points to a pervasive feeling of theoretical support that falls short in practice. I came to this research with questions about how e-learning can be used as a tool of accessibility for students with disabilities. After completing the research process, I emerge with a wholly different set of questions regarding the gaps in support for students with disabilities at the University of Louisville, incongruities which have been established and exacerbated by institutional barriers of inaccessibility.

CHAPTER FOUR: ANALYSIS AND INTERSECTIONS

There is a collective feeling that, with the support of faculty and DRC staff, disabled students should feel supported, so why was that not they case for all of the students I spoke with? Students and stakeholders alike allude to institutional barriers that limit their agency within their roles, though these barriers often remain unnamed and unspecified. The collection of literature that has been my touchstone throughout this research, in tandem with the data I have collected, suggest that these institutional barriers perpetuate existing structures of power and domination, and lead to the consolidation of agency at the top of the power structure. In this case, that power might be seen in committees with fiscal decision-making roles for the university, upper-level administration, or in something less tangible, like society as a whole. Though this may not always be intentional, the social framework in which we all exist is inherently ableist and thus, without the intentional breaking of existing power structures, those ableist structures are extended through time and space (Durban 2022).

The literature around disability and agency, through the lens of anthropology, suggests that the burden of advocacy is heaped onto the student with disabilities, with the expectation that they should be able to “figure it out” and to advocate for their own needs. This perspective disregards the intensive labor involved in self-advocacy and the immense learning about campus resources that must be done before advocacy can take place (Bruce and Aylward 2021). When the literature around disability is largely informed by researchers who are not disabled themselves, there emerges a wide chasm of disconnect between disability research and lived disabled experiences (Battles 2011; Durban 2022; Hartblay 2020; Titchkosky 2011).

The image that individuals with disabilities hold in the observer's eyes partly informs how we see ourselves, so when our experiences of disability are undermined by nondisabled individuals, we begin to doubt our own perceptions of our identity (Dunn and Burcaw 2013; Hartblay 2020). Not only does interpersonal violence undermine disabled identity, but physical and cultural institutional structures do, too (Rosenberger 2020; Titchkosky 2011).

Certainly, some students I interviewed stated that they did feel well-supported. For example, Marissa went so far as to say that her assigned DRC representative was almost like a second therapist and has supported her in ways that she did not necessarily expect. In comparison, some folks such as Diane and Katrina almost felt at odds with the DRC when they had to defend their illnesses and associated needs directly to their instructors, with or without the DRC's assistance. In both of those situations, the outcome was that these students dropped the issue because they were expending energy to defend themselves constantly and did not feel that they were making any progress. The tension between the individual in power, representing the institution at large from the student's perspective, and the student who has their agency limited by institutional roles, becomes negative altogether, and embodies the larger lack of acceptance that people with disabilities can experience (Dunn and Burcaw 2013; Ginsburg and Rapp 2020; Titchkosky 2011).

Not one single student said that instructors or DRC representatives devalue their experiences or neglect their students' needs on purpose, because I do not think anyone believes that. In fact, almost every single student spoke very highly of faculty in general and said that they felt their faculty were supportive. Even though Diane faced difficulty from half of her instructors, she said that this is not representative of her entire experience, as the other half of her instructors were constantly checking in to see if she was doing okay or if there was anything else they could do. Katrina also faced difficulty with certain instructors but said that, overwhelmingly, they have been understanding and sympathetic regarding her disability and associated needs. As students, we mostly encounter faculty with true dedication to their field and cultivating learning in others, and it seems that faculty believe the same of their colleagues.

There were only a couple of testimonies regarding instructors making a student feel uncomfortable, devalued, or othered. At worst, there may be an instructor that, whether consciously or subconsciously, makes the lives of their disabled students more difficult. Accumulated social factors have formed each of these individual’s opinions and values, because, as a society at large, we are not sensitive to the needs of disabled people. Understanding the institutional constraints on their abilities to assist students would help stakeholders’ constituents to better understand why their needs are not consistently being met.

Overwhelmingly, we exist in a world permeated by ableism that assumes individuals are able-bodied (Durban 2022). Something as common as stairs assumes that an individual has functional legs, the stamina to get up the staircase, ample lungs to supply oxygen during the task, and so on. Accepting the reality that we live in an ableist society is not the end of the discussion; in fact, it is just the beginning (Rosenberger 2020). Once we identify and understand the ableism that runs through our society, we can begin to address it appropriately in institutions such as scholarship and learning spaces. To counteract a society of pervasive ableism, the conscious efforts to be inclusive must be more intentional than the prevalent ableism that clings to human social practices.

In the previous chapters, I identified relevant scholarship to the topic of this research and described the experiences of students with disabilities and their stakeholders at the University of Louisville. The rest of this chapter will serve to explore the experiences that have been documented through this research and to frame them in relation to the scholarship on disability, learning, agency, and anthropology.

Gaps in Agency in Disability Resources

First and foremost, assistance through the Disability Resource Center requires formal documentation of a disability from a doctor. No doubt, this is to regulate the influx of students utilizing accommodations and to prevent nondisabled students from taking advantage of resources allotted to those of us with disabilities.

Though I do not have information on the exact limits instituted over the DRC for accommodations, or the number of students that they are currently capable of supporting, I would argue that allowing for accommodations without medical diagnoses would not take away a significant enough amount of resources to make up for the number of students that might need accommodations but cannot access them because they do not have a formal diagnosis for one reason or another. This would expand the agency that all students – both with disabilities and without – have over their own education. Expanding student agency has been proven to be an effective method of increasing success in the classroom, as the increased responsibility instills feelings of capability and trust in students (Eyler 2018; Weimer 2013).

Additionally, according to data published by the National Center for Health Statistics, 12.2% of interviewed adults aged 18-64 years old were uninsured and lacked consistent access to healthcare (Cohen and Cha 2022). This means that many students at UofL could lack access to the medical care which would provide them with a formal diagnosis, effectively preventing them from utilizing the DRC.

Self-Advocacy: The Burden of Labor

Both Diane and August expressed concern for younger disabled people not having the expertise and confidence to advocate for themselves without being asked about that specifically. This is a trap that disabled students seeking disability-related support can often fall into, according to scholarship by Bruce and Aylward (2021). Their research suggests that students with disabilities are often expected to go above and beyond to advocate for themselves and when they do not, this can impact others' perceptions of them, perpetuating "neoliberal-ableist ideals of independence, compliance, and self-containment," (Bruce and Aylward 2021). The gap between the faculty, staff, and peers' expectations of the behaviors of students with disabilities compared with their realistic actions and subsequent reactions can create strained relationships between all parties, which can impact the sense of belonging disabled students feel within their social circles in higher education. As Bruce and Aylward write, "Their experiences expose the pervasive [disablism] disabled students are compelled to endure as a direct result of repeatedly carrying out compulsory acts of self-advocacy in accommodation implementation processes" (2021: 22).

Assuming that students will come to college prepared to advocate for themselves and possessing all the tools to do so is woefully misguided. Students are expected to seek out assistance with the DRC or other resources, but there is no system in place for catching all students and ensuring they are offered support before they begin to struggle personally and/or academically.

Course Format and Quality

The majority of both student and faculty interviewees said that, if they were going to attend or teach a virtual course, they would prefer it be synchronous. However most, if not all, of the University's non-COVID online courses are asynchronous, in which the instructor and the student are further disconnected from one another. There is a consensus between both parties in my interviews that asynchronous courses take much more work and can often be more difficult than synchronous classes, making them the least favorite method of class-taking or -teaching. Teachers stated that it was harder to connect with their students in online courses in general, but especially asynchronous courses, because they were not able to see the student or their body language as they normally would in a traditional classroom setting. Certain social and physical cues from students help to communicate to the instructor if the student is actively learning, for example if the student is distracted or bored, or conversely, if the student is engaged with the content and attentive to classroom activities. "We're mammals. Physical proximity, body language, variations in tone of voice, things like that. Those all matter, so I think you need classroom kinds of activities," Scott noted, and continued to say that it is important to be engaging as an instructor, both online and in-person, but that perhaps it is more difficult to engage with and effectively monitor students online versus in-person.

It seems like instructors and students both have the most difficulty with hybrid and asynchronous online courses. For instructors, these methods require the most frontloading of work and the responsibility to reach out more frequently to their students to ensure that no one is falling behind, which would otherwise be satisfied by regular course meetings where the instructor can check in on the entire class and individuals routinely. For students, these formats require students to pace themselves and to maintain a higher level of responsibility for their own work, which can be particularly challenging if they have not yet had such agency over their own progress.

Though most students and instructors prefer teaching and learning synchronously, Scott has found asynchronous courses to be particularly helpful because students with varying needs are able to access content when it is convenient for them, whether that is because of a job or a disability or any other of a wide range of circumstances. Instructors in VLEs rely heavily on Panopto and similar secured online platforms for posting current and updated lectures in asynchronous courses. Ultimately, the expansion of VLEs, without neglecting traditional classroom learning spaces, connects agency with accessibility by expanding the learning options available to both students and faculty (Eyler 2018; Kyei-Blankson, et al. 2021; Lee 2017; McAvinia 2016; Moreira 2016; Phipps and Merisotis 1999).

Instructors and students alike said that course quality is directly correlated to the practices of the other party: instructors will say a class has gone well if students are participating and engaged, and students will say a class has gone well if their teacher is engaging them with the course material and capturing their attention. This can come down to clear and effective communication as well, making it another commonality in the priorities of both students and their teachers. Diane specifically spoke to the transparency and consistent communication from the sympathetic half of her instructors as the reason she was able to succeed in those courses, regardless of her accommodations being implemented in that course. Both parties, students and faculty, must exercise their agency to engage in coursework and classroom activities meaningfully, actions which can be limited by both disability and institutional barriers (Erickson 1982; Eyler 2018; Titchkosky 2011; Weimer 2013).

The practical limits of the abilities of students with disabilities can impact the experiences of students, their peers, and their teachers. One instructor stated that this is not necessarily a bad thing, and it is a claim backed by scholarship on student agency in learning that all students contribute to and shape their classroom experiences collectively by exercising their agency (Erickson 1982; Eyler 2018; Weimer 2013).

Both students and faculty said that there are buildings on campus that are absolutely not accessible or ADA compliant. Not only is it unacceptable for a public university to have educational facilities such as labs and lecture halls that are not accessible to all students, but it comes off as hostile and wholly uncaring regarding accessibility for physically disabled students altogether (Rosenberger 2020; Titchkosky 2011). Is this representative of universities and institutions of higher education at large?

Reengaging with Identity

The projection of assumed or overgeneralized traits of an identity or social group upon a single individual neglects to acknowledge the dynamic nature of the human experience and overlays an unrealistic image of human existence over reality. In this way, those without disabilities possess privilege not just because of their able bodies but also due to their position in existing power structures, in which people with disabilities are disadvantaged systemically (Battles 2011; Dunn and Burcaw 2013; Hartblay 2020; Titchkosky 2011). Individuals without disabilities do not have to consider the structures that restrict the agency of those with disabilities because it is not a part of their experience.

Participants with other marginalized identities besides disability describe their experiences with their disabled identity wrapped up with other identities such as race and gender. These identities overlap one another and manifest within the existing social structure of general society. Unfettered agency is a privilege in the existing social structures of present-day society. This point is highlighted by the research I have conducted, and is echoed by many other scholars, who attempt to critically analyze the privilege of agency and the groups whose access to such free will are restricted by more powerful institutions. Even when unintentional, the further restriction of access to already-marginalized groups by institutions such as universities further ostracizes the groups that such institutions have often proclaimed to actively include in DEI statements.

Most student participants described that their medical conditions directly impacted their abilities to perform as a student, even if only occasionally. Some participants had experiences so impactful that they were not able to participate in class for a duration of time, but that the only intervention of the university was flag them for unsatisfactory course progress and place them on academic probation. This is a flawed process for two reasons: it does not allow for intervention *before* the student's learning experiences are impacted and it provides no resources for the student to utilize to get themselves out of that situation. This process, as it stands now, restricts the agency of students over their own learning and life in general by limiting the time in which they can recover and thus restricting the options available to them to try to correct their unsatisfactory progress.

Race and Disability

Diane spoke to experiences of being intersectionally Black, female, and disabled forging her into a strong, assertive, and self-advocating individual. "Being a Black female, it's even worse too, because I guess I speak with authority – I'll speak assertive – so sometimes people think I'll come across too aggressive. I'm like, 'No, I'm not aggressive. This is this is telling you that this is what I want. This is what I need.'" In these circumstances, she feels that she gets written off as an aggressive Black woman for confidently advocating for herself, a dismissal that is not only dehumanizing on many accounts, but also gets her no closer to having her needs met. She frequently apologized for her anger and frustration, which I reassured her was not inappropriate or misplaced. I conducted these interviews to hear honest opinions and experiences, and if her experience is anger and frustration and disappointment, then that is what I needed to hear.

The experiences of Black women with healthcare and medical treatment in the United States show inadequacies and chronic undertreatment of genuine health concerns. Black patients are considerably less likely to receive the appropriate treatments during hospitalizations for things such as medical emergencies and cancer, are more likely than white patients to have their pain underestimated by medical staff experience, leading to higher rates of misdiagnosis and subsequent medical error. Racial biases in US medical institutions are so extreme that around 50% of both average, white laypersons and white medical students endorsed some belief in the myths of biological racism, such a belief that Black peoples' blood coagulates more quickly than whites', Black peoples' skin is thicker than whites', or that Black people experience lower levels of pain for the same injury as white people (Hoffman, et al. 2016). Though these beliefs are categorically fictitious and illusory, their prevalence in overall society, specifically medical spaces, is representative of the restrictions imposed upon on the agency of Black Americans by institutional structures and their agents.

These findings align with Diane's experiences with race and disability, as she spoke of being continually misunderstood and misrepresented, and speaks to a larger phenomenon of Black bodies being systemically disempowered in medical and institutional spaces. There is a presumed responsibility for self-advocacy among people with disabilities, particularly in spaces of higher education, but Diane's experiences with advocating for herself are shaded by the interplay of racial and ableist assumptions from institutional agents (Bruce and Aylward 2021).

Gender and Disability

August and Diane both specifically mentioned the intersection between their gender and their disability. It seems like this relationship between disability and gender – and both identities being key pieces of their sense of self – can be a double-edged sword: at times it is empowering and unifying, yet other times, or simultaneously, devastating and lonely. Both Diane and August allude to the relationship between being female/femme and disabled creating a unique pattern together in which your physical discomfort from disability can be presumed to be menstrual or hormonal, and vice versa. This often comes with the connotation of women being presumed to be, in general, more sensitive and less capable due to our physical stature, menstrual cycle, and hormones, among other patriarchal socialized perceptions of women.

The perpetuation of gendered stereotypes functions to limit the agency of women and femmes by restricting their actions and choices outside of roles prescribed to them. With the added dimension of disability, it becomes more difficult for agents on the oppressed side to act outside of their assumed capacities because those in power are rewarded with privilege. Part of privilege is the ability to not be consciously aware of power imbalances because we all, as members of a shared society, are conditioned to act, react, and interact in particular ways through the actions of those around us from birth and throughout our formative years (Harris and Deal 2018). This leaves individuals with the most power to enact change likely unaware of the depth of gendered power structures and their impacts upon those whose agency and power are restricted, highlighting the importance of discussion and education on the topic.

Male privilege and nondisabled privilege go hand-in-hand in the marginalization of feminine, disabled bodies. The intersectionality between these identities means that they inform one another and coexist inextricably in an individual person, though that does not mean that all intersectionally femme and disabled people will have the same experiences. The power dynamics of gender in western institutions have predominantly favored what are presumed to be masculine bodies and qualities over those that are considered feminine such as domination, aggression, physical strength, academic rigor, and so on. By understanding the variability in both gendered and disabled experiences, we acknowledge the agency of all within the spectrums of experience (Dunn and Burcaw 2013; Ginsburg and Rapp 2020: Harris and Deal 2018).

Another example of the intersectional relationship between gender and disability is represented by August, who identifies as autogender, a term that describes their experience of gender through their autistic mind. In their own words, “Autogender [means] that my gender is formed by the identity that my neurodivergent mind has. So, everything about me and how I think of myself is only ever through the lens of how I think, and how I think is autistic.” Autogender is a perfect example of how identity is comprised of many inseparable pieces that are informed by a collection of an individual’s experiences and most accurately aligned with identity by the individual themselves.

On the topic of autism and neurodivergence, the diagnosis of these are prime examples of gendered medical care. Due to the underrepresentation of the perspective of women and those assigned as female at birth (AFAB), many medical diagnoses have historically been founded on the symptoms of men and those assigned as male at birth (AMAB). This ultimately has led to rampant misdiagnosis and underdiagnosis in women and AFAB individuals, particularly in diagnoses based on behavioral symptoms. Women and AFABs with autism spectrum disorder are more likely to try to "camouflage" their presenting behavioral symptoms and mimic others in social situations to fit in (Green, et al. 2019; Harris and Deal 2018).

Concluding Analysis

Disability is impactful upon the experiences of students, and the ways in which institutions and their agents perpetuate the limiting roles placed upon students with disabilities can be further alienating and disabling. Faculty and staff of educational institutions must be willing to accept that, within an ableist culture, the institutions of our society such as universities are inherently ableist and, as such, must utilize their collective agency to act with the intention to be inclusive and anti-ableist in order to have any hope of negating the torrent of ableism that runs through the world around – and within – us. Knowing that we exist in an ableist society and were raised with exposure to ableist ideas comes with the understanding that we ourselves can often be unintentionally ableist which is why it is so important to be intentionally anti-ableist. Without the intentional use of individual and collective agency to break ableist patterns of behavior, agents of action are destined to continue to perpetuate existing cycles, both conscious and unconscious.

CHAPTER FIVE: CONCLUSIONS AND RECOMMENDATIONS

The process of doing this research has been enlightening about my own experiences with disability and given me many opportunities to reflect constructively on my own perceptions of disabled identity and agency. The experiences of the students with disabilities that I spoke to are now immortalized in scholarship through the creation of this written work. Through this research, I have exercised my agency to participate in what the scholars referenced in these pages set out to do in their own works: illuminate and uplift the firsthand experiences of people with disabilities and their closest institutional allies in scholarship directly rooted in our identities and experiences (Battles 2011; Hartblay 2020; Tuhiwai Smith 2012).

When collecting the data for this research, I intended to come up with a list of suggestions for the University of Louisville to implement that could positively impact the wellbeing of disabled students, though I had no idea what those suggestions would look like until the data guided me to them. The testimonies I have collected from students with disabilities and their key university stakeholders, along with my subsequent analysis of the data, have helped me to identity notable gaps in support for students with disabilities and institutional limitations that restrict the agency of the community. In line with this data, I will highlight some of these occurrences and suggest the implementation of appropriate changes and additions to the cultural and institutional landscape of the University of Louisville.

Restricting access to disability resources from those that do not have access to medical care further marginalizes students with disabilities, with or without an official diagnosis, and widens the chasm between us and the nondisabled University community. Changes made to the limitations upon students seeking accommodations requiring formal diagnosis documentation for basic accommodations can expand access to DRC accommodations such as extended test time, quiet testing location, deadline leniency within a reasonable margin. This will expand access to the DRC for students that need it but may not have access to their resources for one of any number of reasons, mitigating the institutional exclusion of already marginalized individuals. This will also increase the agency students are allowed to exercise over their own learning. There is more risk involved in pacing ones' own learning, but the expanded responsibility can be a unique learning experience and provide leniency for students who need it but do not have access to DRC accommodations. Most students that do not need accommodations will not make the effort to seek them out, as some students suggested the process of even asking for assistance is an obstacle to receiving it.

Students that I interviewed specifically mentioned the lack of a dedicated space for the disabled community at UofL. The creation and maintenance of a community space specifically for students with disabilities would help to build community interpersonally between individual students with disabilities and draw in students that may feel marginalized or excluded into the physical institution of UofL as well as fostering relationships between students and the larger cultural institution of UofL. Multiple students expressed a desire for a space besides the DRC that can be utilized by students with disabilities for community-building. Some suggestions for who might house this could be the Student Activities Center or the Cultural and Equity Center, both of which are located centrally in accessible spaces on UofL's Belknap campus.

Students and faculty alike describe the need for VLEs as an option to increase agency and accessibility to educational content for both parties. More courses should be offered synchronously online, as well as in traditional face-to-face modes, so that faculty and students have the option to choose how they would like to teach and learn. This opportunity for choice fosters agency and accessibility for all participants in the learning process for those that see VLEs as an accessible option. The University as an institution and community will further prosper when its members are able to demonstrate their capabilities through agency and begin to thrive themselves.

The process for flagging unsatisfactory progress for students neglects to address any social or personal factors for student difficulties. When students are placed on academic probation, they can be left without financial aid or on-campus jobs that they depend on for the time being, increasing the hardships that students can experience. There should be a process for students in need, especially when dealing with health and disabilities, to receive help and counseling before their learning and grades are impacted. In part, this could be an opportunity to increase the communication pathways between students and their faculty, as both parties in this research suggest that it is an important relationship that needs to be strengthened. To not place this burden solely on instructors, perhaps the DRC or Counseling Center could create positions for individuals who will do regular check-ins with students and faculty to ensure that mental and physical health are prioritized. I specify faculty as well because there is a general feeling that faculty could be better supported by the institution of UofL to serve their students fully. This would also address the student criticism that the Counseling Center does not have the capacity needed to serve such a large University in a timely manner.

Following the thread of institutional assistance for faculty, both students and stakeholders stated that there must be more support for faculty in order for them to support their students to the fullest extent. This should include University-wide trainings on how to support students with disabilities and resources available to both faculty and students to succeed in teaching and learning. The trainings should address sensitivity toward students whose disabilities may impact their learning in ways that an instructor might not necessarily expect, such as invisible illnesses and neurodivergence. Separately but equally importantly, faculty should have full institutional support in learning about technology that can help them expand and diversify their approaches to facilitating learning.

Several faculty members mentioned the frequency with which they must utilize web-based programs and VLEs for instruction, even if they do not teach an online course. A thorough review of the competencies of and communications between Blackboard and other web-based applications that faculty are required to utilize should be conducted with the inclusion of instructor perspectives on the user-friendliness of the programs. Where necessary, smoothing out these technological difficulties could expand the agency of instructors and the accessibility of online course content for instructors and students alike.

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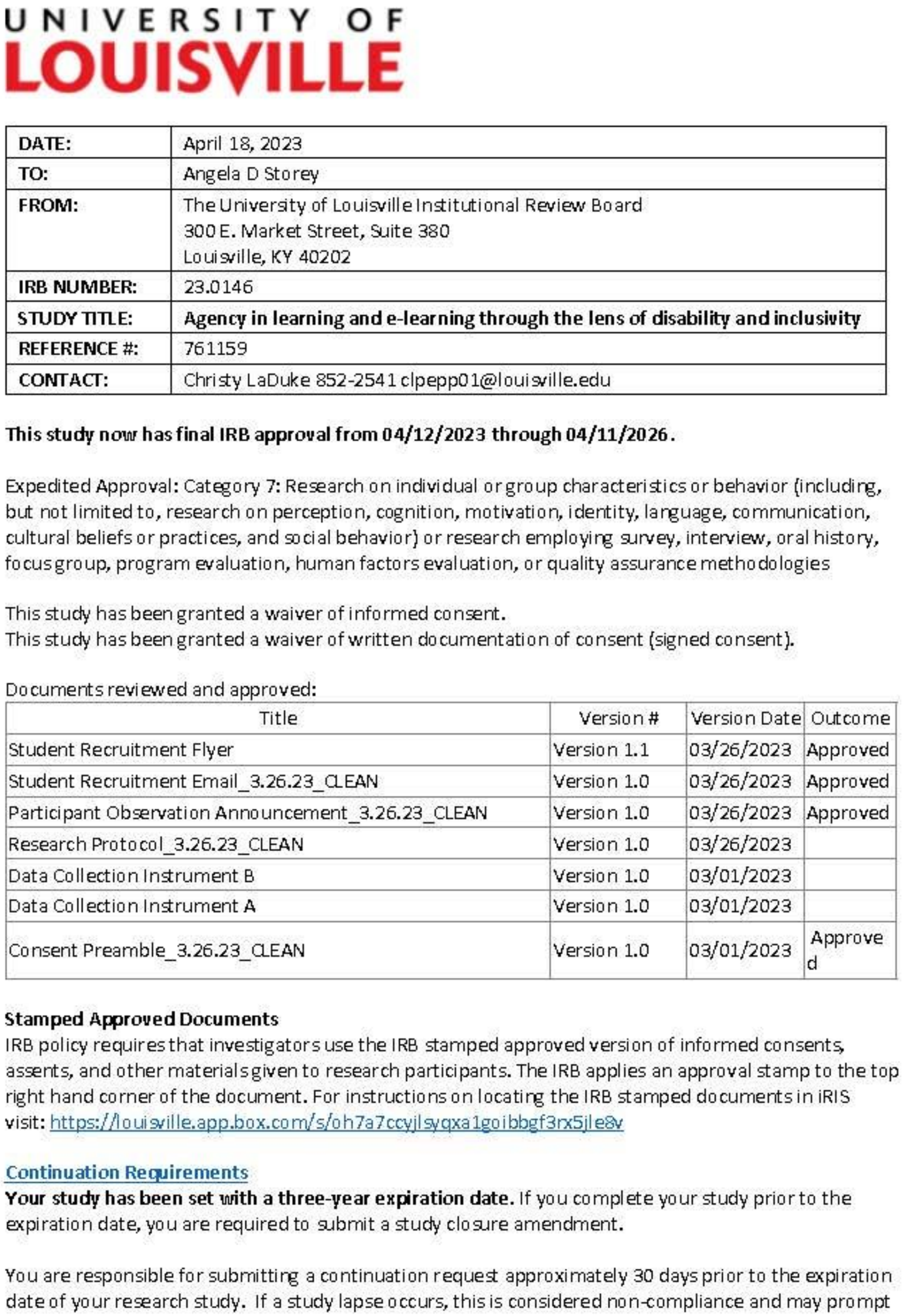

UNIVERSITY OF
LOUISVILLE

DATE:	April 18, 2023
TO:	Angela D Storey
FROM:	The University of Louisville Institutional Review Board 300 E. Market Street, Suite 380 Louisville, KY 40202
IRB NUMBER:	23.0146
STUDY TITLE:	**Agency in learning and e-learning through the lens of disability and inclusivity**
REFERENCE #:	761159
CONTACT:	Christy LaDuke 852-2541 clpepp01@louisville.edu

This study now has final IRB approval from 04/12/2023 through 04/11/2026.

Expedited Approval: Category 7: Research on individual or group characteristics or behavior (including, but not limited to, research on perception, cognition, motivation, identity, language, communication, cultural beliefs or practices, and social behavior) or research employing survey, interview, oral history, focus group, program evaluation, human factors evaluation, or quality assurance methodologies

This study has been granted a waiver of informed consent.
This study has been granted a waiver of written documentation of consent (signed consent).

Documents reviewed and approved:

Title	Version #	Version Date	Outcome
Student Recruitment Flyer	Version 1.1	03/26/2023	Approved
Student Recruitment Email_3.26.23_CLEAN	Version 1.0	03/26/2023	Approved
Participant Observation Announcement_3.26.23_CLEAN	Version 1.0	03/26/2023	Approved
Research Protocol_3.26.23_CLEAN	Version 1.0	03/26/2023	
Data Collection Instrument B	Version 1.0	03/01/2023	
Data Collection Instrument A	Version 1.0	03/01/2023	
Consent Preamble_3.26.23_CLEAN	Version 1.0	03/01/2023	Approved

Stamped Approved Documents
IRB policy requires that investigators use the IRB stamped approved version of informed consents, assents, and other materials given to research participants. The IRB applies an approval stamp to the top right hand corner of the document. For instructions on locating the IRB stamped documents in iRIS visit: https://louisville.app.box.com/s/oh7a7ccyjlsyqxa1goibbgf3rx5jle8v

Continuation Requirements
Your study has been set with a three-year expiration date. If you complete your study prior to the expiration date, you are required to submit a study closure amendment.

You are responsible for submitting a continuation request approximately 30 days prior to the expiration date of your research study. If a study lapse occurs, this is considered non-compliance and may prompt a HSPPO audit.

Human Participants & HIPAA Research training are required for all study personnel. It is the responsibility of the investigator to ensure that all study personnel maintain current Human Participants & HIPAA Research training while the study is ongoing.

Study Site Approval

Permission from the institution or organization where this research will be conducted **must** be obtained before the research can begin (e.g., UofL Health, Norton Healthcare, Jefferson County Public Schools, etc.).

Amendments (Making Changes to the Study)

Prior to making changes to the study, the investigator must submit an amendment to the IRB and receive approval. If the change is being made to ensure the immediate safety and welfare of the participants, refer to the amendments link above for more information.

Reportable Events

The investigator is responsible for reporting certain study events to the IRB within 5 working days.

You are required to follow all University of Louisville policies and procedures related to conducting human subjects research and managing research data. For more information visit: Human Subjects Protection Program Policies.

The committee will be advised of this action at a regularly scheduled meeting.

Thank you,

Peter M Quesada

Peter M. Quesada, Ph.D., Chair
Social/Behavioral/Educational Institutional Review Board

We value your feedback; let us know how we are doing: https://www.surveymonkey.com/r/CCLHXRP

CURRICULUM VITAE

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EDUCATION

MA University of Louisville, Cultural Anthropology December 2023

Advisor: Dr. Angela Storey, Ph.D.

BA University of Louisville, Cultural Anthropology May 2021

Certificate in Peace, Justice, and Conflict Transformation

HONORS AND AWARDS

Virgina “Jenny” Madden Award December 2023

University of Louisville

Anthony X. Flaherty Scholarship Spring 2022

University of Louisville

Dean’s List Spring 2021

College of Arts and Sciences | University of Louisville

EXPERIENCE

Qualitative Thesis Research, University of Louisville | Louisville, KY 2023

Advisor: Dr. Angela Storey | Associate Professor | University of Louisville

Identifying the landscape of the wellbeing of students with disabilities at the University of Louisville, with special attention paid to virtual learning spaces.

Peer Education Program, University of Louisville | Louisville, KY 2022

Advisor: Dr. Angela Storey | Associate Professor | University of Louisville

Taught study sessions for undergraduate students in introductory anthropology courses.
Substitute lecturing one day each for two semesters in ANTH 201.

Archaeological Survey, Old Economy Village | Ambridge, PA 2017

Advisor: Bryan K. Hanks | Associate Professor | University of Pittsburgh

Assisted in the use of GIS equipment and subsequent data review.
Findings indicated potential for long objects buried a few feet beneath the surface of the soil, unconfirmed potential for colonial burial ground.

ACADEMIC AFFILIATIONS

Anthropology Graduate Student Association, University of Louisville, 2021-Present

Anthropology Student Association, University of Louisville, 2020-Present

Disabled Cards United, University of Louisville, 2023

PROFESSIONAL HISTORY

U of L Kroger Scholars

Student Coordinator | Louisville, KY | October 2022 – Present

I oversee communications with students and am their primary resource for assistance through the UofL Zero Hunger | Zero Waste Kroger Scholars Program. I help them every step of the way to develop a research project rooted in sustainability and social justice. I liaise between Kroger and UofL to schedule and communicate important dates, meetings, and presentations. I create and distribute program materials such as introductory information, schedules, presentation guidelines, and so on.

U of L Student Affairs Podcast

Podcast Manger | Louisville, KY | Fall 2022

For this volunteer position, I was responsible for the entire production of the podcast from start to finish. This process included contacting departments and representatives across the University, planning content for episodes with those departments, coordinating meetings with many different schedules, completing the recording process as the host, and finally, publicizing the published content.

Ramona for Kentucky

Staff and Training Coordinator | Louisville, KY | February – April 2020

My primary responsibility the oversight of volunteers and interns, which comprised the bulk of our staff. This position included creating training and onboarding materials, communicating with staff, organizing and recruiting volunteers and interns, creating plans for voter contact, contacting potential voters, and assisting the campaign director and candidate with any other tasks.

Andy Beshear for Kentucky

Field Organizer | Louisville, KY | August – December 2019

I began at this position as an intern, then was offered a field organizing position after a few weeks with the campaign. This position included overseeing volunteers that were assigned to me, organizing and recruiting volunteers, creating plans for voter contact, contacting voters, and assisting the Regional Field Director with any additional tasks. Our candidate ultimately won the governor’s race.

LANGUAGES

English: Native Language

Japanese: Intermediate

Spanish: Novice

SKILLS

Computer: Microsoft Office (Word, Excel, PowerPoint, Outlook, etc.), Digital Art and Design (Concepts and Canva), Adobe Acrobat, social media (Facebook, Twitter, Instagram, TikTok, etc.)

Creative: Writing (Research, Proposals, Exposition, Creative, etc.), Painting, Fiber Arts, Digital Art

Social: Cultural Awareness/Competency, Conflict Transformation, Mediation, Education, Leadership and Management, Communication, Training and Training Materials, Fundraising, Presenting